SPECIAL TIME EDITION

Autism

New Research, New Knowledge • Reality vs. Myth
Understanding the Journey • A Mother's Story

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AUTISM

Pets can be a calming influence for those with autism.

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WHAT IS AUTISM?

As understanding of the disorder deepens and as care improves, we see more clearly what we do not yet know.

BY DAVID BJERKLIE

In the span of a generation, a sea change has occurred in our awareness and understanding of autism. Advances have been made in early diagnosis. Intervention options have expanded. School curricula tailored for students with autism have become commonplace. Popular culture reflects this growing awareness: Memoirs, plays, films, and TV series tell the stories of individuals with autism, which has broadened and deepened the public conversation on mental health and well-being.

The heightened awareness is welcome. But it doesn't mean there is universal acceptance of individuals with autism. And in far too many cases, the awareness hasn't translated into easier lives for those individuals or their families. "The amount of research that's gone into understanding the complexity of autism is enormous," says Cynthia Martin, senior psychologist in the Autism Center at the Child Mind Institute in New York. "We know a lot more about autism now than we did 20, 30 years ago." But, as she adds, it's been the sort of learning curve that also makes it clear how much we do not yet know about the condition.

The term *autism* was coined in 1911 by the Swiss psychiatrist Eugen Bleuler to describe a symptom of schizophrenia, a term Bleuler also coined. Pioneers in the study of the disorder in the 1930s and 1940s included Leo Kanner in the U.S. and Hans Asperger in Austria. It was not until the 1960s, however, that the term acquired its current behavioral associations. As the scientific understanding of autism progressed, perception of the disorder and its treatment were shaped by a variety of societal factors. And yet answers to fundamental questions about what causes autism and why its prevalence is rising remain frustratingly incomplete.

Research shows autism has a strong genetic basis—more than 100 different genes have been implicated—though its hereditability is complex. Most cases are believed to be driven by interactions among multiple genes and the environment, including the prenatal environment. Risk factors include parental age, maternal type 2

diabetes and hypertension, and prenatal exposure to infection.

The current definition of autism spectrum disorder, according to the National Institutes of Health, is "a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave." It is considered a developmental disorder because symptoms generally appear in the first two years of life, although later diagnosis is common.

The definition is broad. As Adriana Di Martino, MD, the founding research director of the Autism Center at the Child Mind Institute, notes, "one of the major challenges to a deeper understanding of the underlying mechanisms of autism and its care is its striking . . . variation among individuals."

The medical community acknowledges that putting a fine point on what autism is—and isn't—is easier said than done, even when it comes to basic parameters. In 2013, the American Psychiatric Association published the 5th edition of its *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. Recognizing that severity affects type and intensity of treatment, the manual attempted to offer guidance. "*DSM-5* required all disorders to have severity levels," says Catherine Lord, PhD, professor of psychiatry at UCLA's Semel Institute of Neuroscience and Human Behavior. "And so the committee came up with three levels, but as they stand, they… often don't mean much."

The intent behind establishing three levels was understandable, notes Lord, but fraught. Problems arise when assignment to a diagnostic level does not reflect the actual clinical needs of the individual or family. "To use severity of social difficulties or restricted/repetitive/sensory behaviors doesn't really work, because expectations and needs, at least for different social behaviors, differ greatly across age and contexts," she says.

Diagnosis can be controversial in other ways. "We're getting to the point where we're thinking that anybody with an interpersonal challenge or anybody who has discomfort in social situations might be that way because they're autistic," says Martin. No one wants to miss a case of autism. But it is difficult to devise a test sensitive enough to capture all cases of autism and also specific enough to exclude cases that should have a different diagnosis. "We are all on the same team in wanting to identify and help people who have autism," says Martin. And yet, right now, "we're overshooting on diagnosing cases at the very mild end of the spectrum."

The broadening and blurring of diagnostic criteria are also factors in prevalence numbers going up. According to data from the Centers for Disease Control, the prevalence figure now stands at 1 in 31 kids being diagnosed; in 2000, it was 1 in 150. A generation ago, diagnoses were distributed among various conditions: autism disorder, Asperger's syndrome, pervasive developmental disorder–not otherwise specified (PDD-NOS), all of which could be accompanied by varying degrees of intellectual disability. The decision to combine them in *DSM-5* under the single diagnosis of autism spectrum disorder was done because the division into subgroups wasn't consistently applied, explains Lord. A very young child might be diagnosed as PDD-NOS and then be given an autism diagnosis at school age and an Asperger's diagnosis at adolescence.

That doesn't mean those distinctions aren't real, Lord says, but it is also clear that some diagnoses are either more or less scary-sounding than others.

"Autism has come to be seen, at least in Western countries, as a preferred diagnosis," she says.

Complicating things even further is the fact that autism is often correlated (comorbid) with some other traits and conditions, including attention and anxiety disorders. Comorbidity may increase with age and make intervention and treatment more difficult. "Because there are such high rates of co-occurring psychopathology, you have to be able to figure out, basically, where the autism starts, where the other condition begins, and then how do the two interact with one another?" Martin says.

There are also concerns over diagnosis for the most severely affected. A growing advocacy effort, led by parents, aims to have a separate diagnostic category established, called profound autism. This diagnosis, says Martin, would serve individuals who have been largely left out of the public conversation surrounding autism. "These are individuals who have very limited verbal skills, need round-the-clock support, and are potentially prone to self-injurious behaviors," she says. Such individuals are also often left out of research. "These kids are difficult to enroll in research studies," Martin adds. "There are significant barriers. And yet we need more funding and attention to that group specifically because they have the highest level of needs."

One of the many impacts that autism awareness has had on society is the ubiquitous use of the word *spectrum*. And while the metaphor of a spectrum reflects the diversity and gradations of symptoms within autism, it is an image that can lead to misunderstandings and oversimplifications.

"Yes, a spectrum communicates that there is going to be variation," Martin says, "but the way the spectrum usually gets interpreted is that it is linear—it goes from 0 to 10, from very mild to very severe. But autism is more complicated than that. Think of the difference between an oven and a stovetop. An oven is set at a single temperature; it can be low or high, but it can't be at 250 degrees and 500 degrees at the same time. But with a stovetop, you have four burners, and you can have different combinations in which one burner is off, one is on high, one is on low, and one is in between." Autism is more like the stovetop, where some symptoms may be mild, others more severe, and yet others either in between or not present at all.

What does the future hold? More research, certianly. "I know this is a dream," offers Lord, "but I would love to see autism have centers where researchers across the country would work together on studies that would let us better address the heterogeneity in autism." Di Martino envisions more research that allows doctors "to identify those individuals more likely to respond to a given intervention while also elucidating underlying mechanisms of change." As she sees it, "I cannot underscore more the value of science, including basic science, for progress."

There are many things yet to be discovered about autism, only some of which can be anticipated today. Our societal awareness of autism will also continue to evolve. We should not expect—or even want—all of the disparate voices surrounding autism to become a single, uniform perspective. Autism provides us with a model of how complicated and challenging human interaction can be.

Says Lord, "Having a child with autism radically changes almost everyone's life in a family. And though there are joys and wonderful moments, it's wrong to pretend it's easy." □

DIAGNOSING & TREATING

Identifying autism in young people is the first step in caring for them.

Reality vs. Myth

As rates rise, so do the claims about what causes autism. Here's a look at what is known about the disorder.

BY SARAH KLEIN

THERE IS NO SINGLE ROOT CAUSE FOR autism. That fact is an alarming one, especially to parents of newly diagnosed children. "Parents, particularly parents who have kids who are more severely affected, are desperately trying to figure out, 'Why did this happen, and can I do something to help it?'" says Carol Weitzman, MD, codirector of the Autism Spectrum Center at Boston Children's Hospital.

This has led to a lot of questions about the causes and risk factors of this neurological and developmental condition. "All of the questions that the public has are valid," says Jonathan Sebat, PhD, director of the Verge Center at the University of California San Diego and a professor of psychiatry and cellular and molecular medicine. In many cases, he adds, "science has specific answers, even if we don't understand it completely."

The lack of complete understanding of autism has led to lingering myths and misconceptions, many of which have become controversial and politicized. Sebat thinks addressing these misconceptions requires more nuanced communication from scientists, physicians, government organizations, and the media. "We need [explanations] that don't insult the intelligence of the public and do a little bit of a deeper dive into answering their questions," he says.

Here is an overview of what does and what does not cause autism—and what it might take to put these myths to rest once and for all.

FACTORS LINKED TO AUTISM

Considered a developmental disorder, autism "affects how people interact with others, communicate, learn, and behave," according to the National Institute of Mental Health.

Autism spectrum disorder (ASD) diagnoses have increased from 1 in 150 in 2000 and 1 in 68 in 2010 to 1 in 31 in 2022, according to an April 2025 report from the Centers for Disease Control. This is due to better testing for the condition, as well as an increased awareness of the disorder, along with a decrease in the amount of stigma once attached to

Genes account for 80 percent of the risk of autism, and variants in more than 100 genes have been identified as playing a role.

Higher parental age, diabetes, obesity, and immune system issues during pregnancy are linked to higher chances of having a child with autism.

Autism starts during the prenatal period. It's not something where a child is developing normally and then, later in life, an environmental risk factor occurs, and then they develop autism."
—GERALDINE DAWSON, PHD

discussing the symptoms. At the same time, there is a better understanding of certain environmental factors that are linked to autism.

GENES

By and large, autism is a genetic condition. Autistic people generally have any number of genetic variants that, when coupled with environmental factors, lead to symptoms. Some research estimates that genes account for about 80 percent of the risk of autism, and variants in more than 100 genes have been identified as playing a role.

Some of these gene variants are quite common, and it takes a number of them to accumulate beyond a certain threshold to cause autism, says Geraldine Dawson, PhD, founding director of the Duke Center for Autism and Brain Development and the William Cleland Distinguished Professor of psychiatry and behavioral sciences at Duke University. Others are rare and spontaneous, and those gene variants in an autistic child might not be present in their parents.

Either way, the genes that lead to an ASD diagnosis are there when a baby is born and at work even before then. These genes "are highly expressed during fetal brain development," says Dawson. "They have to do with how neurons are formed, how they're organized, as well as how they function. This is a really important finding, because it tells us that autism starts during the prenatal period. It's not something where a child is developing normally and then, later in life, an environmental risk factor occurs, and then they develop autism."

A person can be diagnosed with autism at any age, but symptoms typically begin before a child turns 2. These early signs often involve a regression of skills, meaning a young child who had been hitting age-appropriate milestones begins to lose those skills. That's not a familiar timeline for a genetic condition to many people, Sebat points out. Instead, they expect symptoms would have always been present, and therefore they tend to write off a genetic cause for autism and look to some other factor to blame.

But newer research suggests babies may have had symptoms of autism—or have at least been experiencing the effects—since birth.

These studies look at the earliest experiences of children who have gone on to be diagnosed as autistic. For example, in one 2023 paper, medical records show that autistic children were already going

Premies have higher rates of the disorder, with those born at 22 to 27 weeks almost four times as likely to be autistic as babies born at full term.

to many more doctor's appointments as early as 30 days after birth compared with kids who were not later diagnosed with autism. "I think this is a really important [area of research] that helps parents understand" some of the early signs, Dawson says. "It's very inconsistent with the idea that at 12 months of age, your child receives a vaccine and then has autism."

ENVIRONMENTAL FACTORS

Genes are an important part of the cause of ASD, but autism is not entirely inherited. "In most cases, both rare and common genes are adding together to contribute to the likelihood of autism, but these are also combined with environmental factors," Dawson says.

The gene-environment relationship is still an area of ongoing research, and environmental factors are particularly challenging to study because they're difficult to isolate. Plus, observational studies of environmental factors can typically only show correlation, not causation.

That said, there are now several environmental factors that are linked to autism risk based on solid scientific backing:

Parental age at conception. Parents older than 40 are more likely to have a child with autism. "As we age, we accumulate tiny deletions to our chromosomes," Dawson says, due to our own exposure to toxins, medications we take, even our diet. If those changes occur in genes associated with autism risk and they are passed down to a child, there may be a higher likelihood of autism.

Preterm birth. Babies born prematurely have higher rates of autism. Premies born at just 22 to 27 weeks are almost four times as likely to be autistic than babies born at full term, at 39 to 41 weeks, according to a 2021 study in *Pediatrics*. Babies born very early often have lower birth weight than babies born at full term, and a lower birth weight is associated with a number of developmental conditions. "And that makes sense: You have a child who is born very early, and that's associated with a lot of impact on brain development," Dawson says.

Birth complications. Knots in the umbilical cord, the placenta tearing away from the uterus, and other concerns can deprive a fetus's brain of oxygen, which affects brain development and is associated with a higher likelihood of having an autistic child. Sometimes complications result in a baby having to spend time in the neonatal intensive care unit (NICU). Babies who experience a NICU stay are also more likely to have autism. "A large fraction of them actually have genetic disorders that contributed to being admitted to the NICU in the first place, so you have this direct interplay between genes and environment," Sebat explains.

The pregnant mother's health. Obesity, diabetes, and problems with the immune system during pregnancy are linked to higher chances of having a baby with autism. "The theory is that conditions that lead to chronic inflammation and immune system dysregulation in the mother can affect fetal brain development," Dawson says. And just as pregnant women are urged to get enough folic acid to ward off birth defects, nutrient intake is also associated with autism risk. Ensuring you have adequate levels of important compounds such as folic acid and vitamin D may make you less likely to have an autistic child.

Air pollution. Exposure to such environmental toxins as smog during pregnancy raises the risk of having a baby with ASD. The theory is that pollution and other toxins increase inflammation in the pregnant woman, which then affects a fetus's brain development.

Having another child in the family with autism. This points to the complex interplay of genetic and environmental factors involved. "Even though the environments may be the same, one child may present with a very specific profile, and the other child may present with a broader autism phenotype," Weitzman says.

FACTORS THAT DO NOT CAUSE AUTISM

The biggest myth about what causes autism is that vaccines—specifically the measles, mumps, and rubella (MMR) vaccine—are a trigger. Vaccines do not

Exposure to environmental toxins during pregnancy raises the risk of having a baby with autism.

cause autism. This idea first came to light in the late 1990s in a very small study, by British physician Andrew Wakefield, funded by lawyers working on behalf of parents suing vaccine manufacturers. Wakefield falsely linked the MMR vaccine to autism. His paper was eventually retracted by the journal that published it, and he lost his medical license. Numerous large studies have since shown no link between vaccination and autism.

But part of why this myth lingers is because MMR vaccination and autism diagnosis do tend to occur around the same time. "The timing of when most children receive the MMR vaccine happens to coincide with when parents may notice some early signs of autism," Dawson says.

It's important to stress that parents aren't imagining this, Sebat says. "They really did see a [healthy] trajectory up until 12 months, and then shortly after the shot, or maybe even immediately after the shot, they might see a loss of skills," he says. "But the long-term outcome is not influenced by the shot. It's determined by the gene."

Unsupported myths that bad parenting, plane contrails, or certain foods in a baby's diet cause autism also persist. And this list is not nearly exhaustive. Weitzman says she hears about new hypotheses from parents about unproven causes of and treatments for autism every day. "There is an ever-expanding list of things that people put out there. And the people who are selling these treatments speak with great authority about them," whether on social media or in reputable news outlets, she says.

Weitzman thinks it's possible clinicians can be proactive and ward off some of these misconceptions before a family considers an alternative treatment or believes and then spreads an unfounded claim about the cause of autism. She experiments with saying the following: "There was a big piece about blank in the news. Have you heard about it? Do you want to talk about it? Do you want my opinion about that?" This can help open the door to conversations parents may have been nervous to have with their physician.

There's also the barrier of time. It can be challenging to communicate all of this to concerned parents in the span of one brief visit to a pediatrician. Those too-short visits may therefore contribute to a decline of trust in science and medicine. Dawson sees this lack of confidence as a major driver of the questions and misconceptions surrounding the causes of autism.

Rebuilding that trust is key in getting through to parents who are steadfastly opposed to their children receiving needed and lifesaving vaccinations, Dawson says: "This likely begins with the relationship between the family and their pediatrician. But as scientists, we need to work on this [too], because it won't matter how many studies we do if people don't trust us."

The biggest myth about what causes autism is that vaccines—specifically the measles, mumps, and rubella (MMR) vaccine—are a trigger. Vaccines do not cause autism.

WHERE WILL RESEARCH GO NEXT?

U.S. Health and Human Services secretary Robert F. Kennedy Jr. has long touted the disproven claim that there is a link between vaccines and autism, and in April he announced that he was launching a massive new study to discover the reasons for the increasing rates of autism (see page 32 for more). Scientists who have long searched for a cause are skeptical about his plan. This idea is "distressing," says Weitzman, because "it is elevating misinformation that has already been shown to not be related to the cause of autism." It leads to further distrust in vaccines, physicians, and medicine while detracting from researchers' ability to explore new areas of study that have the potential to lead to more effective interventions, she says. "There's a list a mile long that we should be investigating in a disorder we still know so very little about."

Dawson agrees. "This would slow down our ability to make these important medical discoveries that really could improve the health of everyone. This is such an exciting time for medical research, given the advances in genetics and technology and AI. And so we want to make sure our precious resources are being used to develop better ways to detect autism…and treat autism." ◻

Are Rising Numbers Cause for Alarm?

PUBLIC FEAR IS UNDERSTANDABLE, BUT EXPERTS SAY THE TREND IS ACTUALLY EVIDENCE OF SUCCESS.

BY DAVID BJERKLIE

If there is a single fact everyone "knows" about autism, it is that numbers are rising—dramatically. The increase has fueled speculation about its cause, including wildly unfounded theories that persist on the internet. The story behind the numbers is complex, and while researchers would like some of their questions answered more fully, many considerations put the increase into context.

In 2000, the CDC began to collect national data in the Autism and Developmental Disabilities Monitoring Network. The prevalence of autism at that time was estimated to be 1 in 150 children. By 2016, the number had risen to 1 in 54, and according to the latest data, it now stands at 1 in 31. Tracking the prevalence of autism is an imperfect science. For example, the 1 in 31 estimate is based on data collected among roughly 9,000 children ages 4 to 8 from 16 sites across 15 states in 2022. Prevalence ranged from a high of 1 in 19 in California to 1 in 103 in Texas.

That has shed light on patterns of diagnosis in terms of race, ethnicity, gender, and age, as well as other diagnostic subcategories. A 2023 Rutgers University study published in *Pediatrics* found that in New York and New Jersey, the number of 8-year-olds diagnosed with autism who did not have accompanying intellectual disabilities rose significantly more than those who did. A 2024 study, published in *JAMA Network Open*, found that individuals ages 26 to 34 saw the sharpest rise, with rates increasing in a decade by 450 percent.

Well-known factors have contributed to increasing prevalence. Heightened awareness and media attention have led to greater recognition of signs and symptoms. Increased access to screening has allowed earlier identification, and improvements in data collection have resulted in more comprehensive databases.

Another key factor has been the expansion of diagnostic criteria for autism. In 1980, autism was included as a distinct category in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-3),* and in 1987, a revision broadened the diagnostic criteria. In 1994, the *DSM-4* introduced the concept of an a spectrum, which included diagnostic categories like Asperger's syndrome, which had been previously considered separate. In 2013, *DSM-5* added severity levels to the definition of autism, which helped to broaden the criteria further. The 2022 revision of *DSM-5* improved the clarity and consistency of the diagnostic criteria, making it easier for clinicians to apply them in a consistent manner.

While it's understandable that the public is concerned about the rising numbers, Andy Shih, chief science officer at the advocacy group Autism Speaks, feels it is evidence that research work is paying off. In reference to the research results published in *JAMA Network Open*, Shih wrote: "It shows where we're making progress, but also where we need to improve." Bridging gaps in healthcare access, notes Shih, is where the focus should be.

Even as researchers continue to investigate the factors responsible for the rise of autism numbers, diagnostic trends will impact healthcare delivery and educational practices, including training and integration of support services in schools and communities. The higher numbers will increase scientific attention and research funding, as well as the need for support networks and advocacy groups.

Research has found children who begin support at 18 months show more than twice the improvement on social-skills tests than those who started nine months later.

Early Signs of Autism

Timing matters. Here's what to watch for—and when and how to take action.

BY HOLLY PEVZNER

While the signs of autism spectrum disorder (ASD) often appear early, research shows that many families wait until their child is between 8 and 28 months of age before starting to seek answers. And even after that initial screening, the path to diagnosis often stretches out another two-plus years.

This hesitation is natural. Every child develops differently, and "parents can be resistant to the diagnosis because of stigma or even denial," says Sanam Hafeez, PsyD, a neuropsychological assessment specialist and director of Comprehend the Mind in New York City. Yet timing can dramatically affect outcomes. A 2023 study in the journal *Autism* found that children who began support at 18 months showed more than twice the improvement on social-skills tests than children who started just nine months later, exhibiting major gains in language, social skills, and cognitive development. "Early intervention leads to the most positive outcomes in all areas of functioning," says Hafeez. Understanding what to watch for and where to turn for help can transform a child's future.

EARLY SIGNS OF AUTISM

Children with ASD often hit major physical milestones like sitting, crawling, and walking on time. But subtler differences in development and interaction are the crucial signs. "Often, the clues aren't so much what kids are doing but what they're not doing," says Christina Toolan, PhD, an assistant professor of child development specializing in autism at California State University, Dominguez Hills. "This can mean a child who rarely meets your gaze, doesn't respond to their name, shows few facial expressions, or doesn't share back-and-forth exchanges of smiles and sounds. Limited language or gestures, like pointing, can also signal a difference." These behaviors fall into what experts call joint attention, and delays here are one of the biggest autism tells, according to the American Academy of Pediatrics (AAP).

Parents often also notice restricted and repeti-

tive behaviors. "These include activities like pushing a toy back and forth repeatedly, spinning, rocking, hand flapping, or focusing intensely on just parts of an object, like the wheels of a toy vehicle," says Toolan. "Sensory interests or aversions, such as fascination with blinking lights or touching objects to their lips, or strong reactions to food textures, are also common."

KEY AUTISM SIGNS BY AGE

TODDLER SIGNS (18 months to 3 years)

- Doesn't respond to their name
- Unusual eye contact
- Doesn't follow pointing/share attention
- Has little interest in interactive play
- Rarely shares excitement or shows things
- Prefers solitary play (after age 2)
- Repeats words without clear purpose
- Repetitive movements (flapping, rocking)
- Unusual toy play (spinning, lining up objects)
- Strong reactions to changes in routine
- Sensitive to textures (food, clothing)
- Intense focus on specific objects

SCHOOL-AGE SIGNS (4 to 12)

- One-sided conversations
- Limited interest in social connections
- Trouble with emotional expression
- Misses social cues/body language
- Unusual speech patterns (monotone or singsong)
- Uses scripted phrases from movies/shows
- Requires fixed routines
- Intense, narrow interests
- Struggles with change

"Often, the clues aren't so much what kids are doing, but what they're not doing," says Christina Toolan, PhD.

Some of these behaviors don't automatically indicate autism. "It's never just one characteristic," says Agnesa Papazyan, PsyD, a pediatric psychologist and clinical director at SoCal Psychology Center in Sherman Oaks, California. "We look for a variety of signs." If your child loves to precisely line up toys, that alone doesn't suggest autism. What matters is the overall pattern of development and getting expert guidance to understand what you're seeing.

UNDERSTANDING AN AUTISM ASSESSMENT

Unlike testing for common childhood illnesses, assessing autism requires careful observation of behavior patterns and development over time. The process often begins at the pediatrician's office, where the AAP recommends autism screening during 18- and 24-month well visits.

While these screening guidelines are crucial for early identification, Toolan points out that "there's no standard way to screen for autism across pediatric practices. Some doctors use one tool, some use another, and some don't screen regularly at all." Despite doctors being trained and given the right tools, a 2024 report found that many still tend to only screen toddlers who show the most obvious signs of the disorder. As a result, subtler cases often go unnoticed until later.

Still, your child's pediatrician remains your first line of support. "Parents should feel empowered to

ask about autism screenings at the recommended intervals," says Dannah Raz, MD, chief of developmental pediatrics at Phoenix Children's Hospital. "If your parental instincts aren't being heard, it's okay to consult another pediatrician." This proactive approach is critical, notes pediatrician Kristin Sohl, MD, founder of ECHO Autism, a virtual learning network connecting physicians with autism specialists. "When there are questions about development, don't watch and wait. You need to keep moving forward," she says.

EVALUATION OPTIONS

Your doctor can refer you to specialists such as a developmental pediatrician or neuropsychologist for further testing, but there are other routes. For children under 3, state intervention programs offer free evaluations. School-age children can receive free assessments through the public school system. "State and school evaluations may not specifically diagnose autism, but they can identify the need for services or further assessment," says Hafeez.

Private evaluations—though costly, at up to $7,000 without insurance—can provide comprehensive assessment, including a medical and behavioral history review and structured observations. "This type of assessment can include a cognitive measure, where a child completes certain tasks," says Raz. The gold-standard autism assessment combines the play-based Autism Diagnostic Observation

If your child loves to precisely line up toys, that alone doesn't suggest autism. What matters is the overall pattern of development and getting expert guidance to understand what you're seeing.

Schedule (ADOS) with the Autism Diagnostic Interview-Revised (ADI-R), a structured parent interview about the child's developmental history.

According to Hafeez, the full evaluation process should run about four to six months. "After we do testing—usually over two half-days—we check in several months later to see what suggested interventions worked, what hasn't," she says. This part of the process helps distinguish autism from other similar or overlapping conditions—and from normal neurological maturation.

GETTING TO DIAGNOSTIC CLARITY

Research shows that the accuracy of autism diagnosis rises sharply with age. At 12 to 13 months, diagnostic certainty is about 50 percent, but it jumps to 83 percent by 16 months. "Before age 3, autism is a provisional diagnosis, meaning the diagnosis is a working hypothesis," says Hafeez, who notes that the intense pace of early childhood development can make definitive diagnosis challenging. While diagnoses may evolve, don't let the word *provisional* stop you from accessing support. Early intervention is crucial during this window of rapid brain development, whether the initial diagnosis changes or not. "Early intervention services, like speech and occupational therapy, are worth their weight in gold," Hafeez says. A 2022 report found that children who got support before age 3 scored nearly 14 points higher on social skills tests, more than twice the progress compared to those who started later, who gained only about five points.

Sometimes autism can be missed or confused with other conditions. "Children initially diagnosed with ADHD are three times more likely to be diagnosed with autism after age 6," says Raz. "Since ADHD and autism commonly coexist, identifying one should prompt thorough screening for the other." This often becomes apparent around second or third grade, when social challenges become more visible. At the same time, ASD can become the default diagnosis for other challenges, which is why Hafeez recommends reevaluation for some children every 18 to 24 months.

DIFFERENCES BETWEEN BOYS AND GIRLS

Autism presents similarly across boys and girls, but there are some key distinctions. "Girls often mask their challenges by mirroring others' social behaviors, and their intense interests—like animals or art—appear more typical than boys' focused interests in things like trains or numbers," says Papazyan. This masking ability can lead to misdiagnosis as anxiety or ADHD, resulting in girls receiving autism diagnoses about three years later than boys, according to a report in the journal *Frontiers in Psychiatry*. The effort of masking frequently leads to additional anxiety and emotional challenges.

FIRST STEPS AFTER DIAGNOSIS

An autism diagnosis brings intense emotions, but as Toolan reminds parents, "nothing has changed about your child—they're still your kid." Rather than worry about labels, Raz suggests viewing the diagnosis as a key to understanding: "It'll help you better recognize who your child is and why things may be different for them." Most important, "securing support early is never the wrong answer. You can back off as needed, but you can't go back in time and start intervention earlier."

If you haven't already done it, and your child is younger than 3, contact your state's early intervention program for free services. For older children, "request a school-based assessment to help determine whether your child needs an Individualized Education Program [IEP] or special services," says Papazyan. While public schools provide these services, private schools may not. Toolan recommends Autism Speaks' free online 100 Days Kit.

Your child's intervention plan should combine multiple approaches: behavioral therapies like applied behavior analysis (ABA), developmental services like speech and occupational therapy, and educational supports. "Wait lists for services like ABA can be really long," notes Toolan. Her advice: Contact behavioral intervention providers while working with your school or early intervention program to avoid losing valuable time.

As you move forward, know that you're key to this process. Parent training will teach you new ways to help your child communicate and interact, but balance is essential. "You're a parent, not just an interventionist. It's not only okay but important to just be family sometimes," Toolan says.

Taking care of yourself is equally key. Parents of children with autism who build a support network experience less stress and better well-being. With the right medical professionals, educators, and therapists, as well as close and reliable friends and family, your child and your family can thrive. □

Treating Autism

A wide range of tests can now identify the disorder in children. That has proven essential in determining the best early therapies.

BY LISA PIERCE FLORES

By the time Jane and Amir Nizam's son was 20 months old, his parents noticed that he was quieter than most children his age. He was also hitting developmental milestones—sitting up, standing, walking, and talking—a bit later than expected. Other behavior patterns were more concerning. He would stare up at the ceiling fan, transfixed by the movement; open and close doors for extended periods; and, at bedtime, bang his head against the mattress repeatedly until he fell asleep. "We saw these behaviors, and none of them on their own are that worrisome, but you add them together, and they just didn't feel right," Amir says.

The Nizams sought out a developmental pediatrician. After their son underwent an array of tests designed to assess his social, cognitive, and interpersonal behavior, they learned that his head banging was a form of stimming, or self-stimulating behavior. The repetitive movement helped him soothe his overactive sensory processing system and is a product of his level 2 autism.

DIAGNOSIS: WHAT TO EXPECT

There are two pathways families like the Nizams can take toward getting an autism diagnosis: medical and educational. Both tend to use the same diagnostic tools, including a widely used assessment called the Autism Diagnostic Observation Schedule (ADOS) that consists of play-based tasks designed to assess social and communication skills.

"My idea in the ADOS was to set up little situations for the children. I didn't want to direct them but rather offer them a range of activities, to play with them," says Catherine Lord, PhD, currently the George Tarjan Distinguished Professor of Psychology and Education in the David Geffen School of Medicine at UCLA, who in the 1980s led the team of researchers that created the diagnostic tool. "I had a basket of toys and items, and I would allow each child to choose which item they wanted to interact with." Using ADOS, Lord and her colleagues observed which objects the children selected, how they played with them, and whether they attempted to engage the clinician in their self-directed play.

A center in Gland, Switzerland, uses applied behavior analysis (ABA) to help increase helpful behaviors and decrease harmful ones.

If the child had language, researchers noted how they talked about the object. Did they babble to themselves, use words, direct their gaze toward the clinician and try to get them involved in the "conversation"? Over time, the clinicians noted that autistic children played in very different ways than children who had not received that diagnosis. Using those differences, Lord and her colleagues created ratings based on factors such as engagement, fixation, and object preference.

Since its publication in 1989, the ADOS has become a widely accepted autism assessment tool. Its five modules are used to diagnose autism in patients from 12 months to adulthood. But a behavioral assessment like ADOS is just one element in an effective study.

Other elements include caregiver interviews using tools such as the Autism Diagnostic Interview-Revised (ADI-R), which Lord also helped to develop; the Modified Checklist for Autism in Toddlers (M-CHAT); the Childhood Autism Rating Scale (CARS); the Gilliam Autism Rating Scale (GARS); and the Vineland Adaptive Behavior Scales, Third Edition (Vineland-3). Assessments designed to gauge cognitive ability, such as the Wechsler Intelligence Scale, are also part of the mix.

Taken together, these tests and observations are used to diagnose a child or adult with autism and predict the level of support they are likely to need to optimize their social and educational opportunities and maximize safety and autonomy. The key to the process is the trained clinician, yet there simply aren't enough of them to meet demand. In some parts of the country, wait times for assessments can stretch to 18 months or more.

BIOMARKERS AND GENETICS

Because of the shortage of clinicians, James McPartland, PhD, director of the Yale Developmental Disabilities Clinic and the McPartland Lab at the Yale Child Study Center in New Haven, Connecticut, has partnered with Duke University, Boston Children's Hospital, the University of Washington/Seattle Children's Research Institute, and the Children's Hospital of Los Angeles to create the Autism Biomarkers Consortium for Clinical Trials. McPartland's research group uses such biomarkers as eye-tracking and brain-wave monitoring.

Research shows that when compared with neurotypical babies, autistic babies are more drawn to patterns than they are to people. Using this preference as a starting point, a team led by Karen Pierce, PhD, a professor of neurosciences at the University of California San Diego, has created a technology that presents babies with two video images. One displays a sequence of geometric shapes, and the other presents more socially focused images, such as babies interacting with their mothers. When compared to more traditional measurements, babies who direct their gaze toward geometric shapes rather than other children 60 percent or more of the time end up receiving an autistic diagnosis nearly 100 percent of the time. "You can do eye-tracking with any baby at any level of development. They don't need to talk, babble or sit up," Pierce explains.

Pierce is similarly collecting data using brain wave monitoring via electroencephalogram (EEG) and tracking how babies direct their gaze when they hear women using "motherese," the kind of infant-directed musical speech that is used by caregivers around the world to engage and soothe babies.

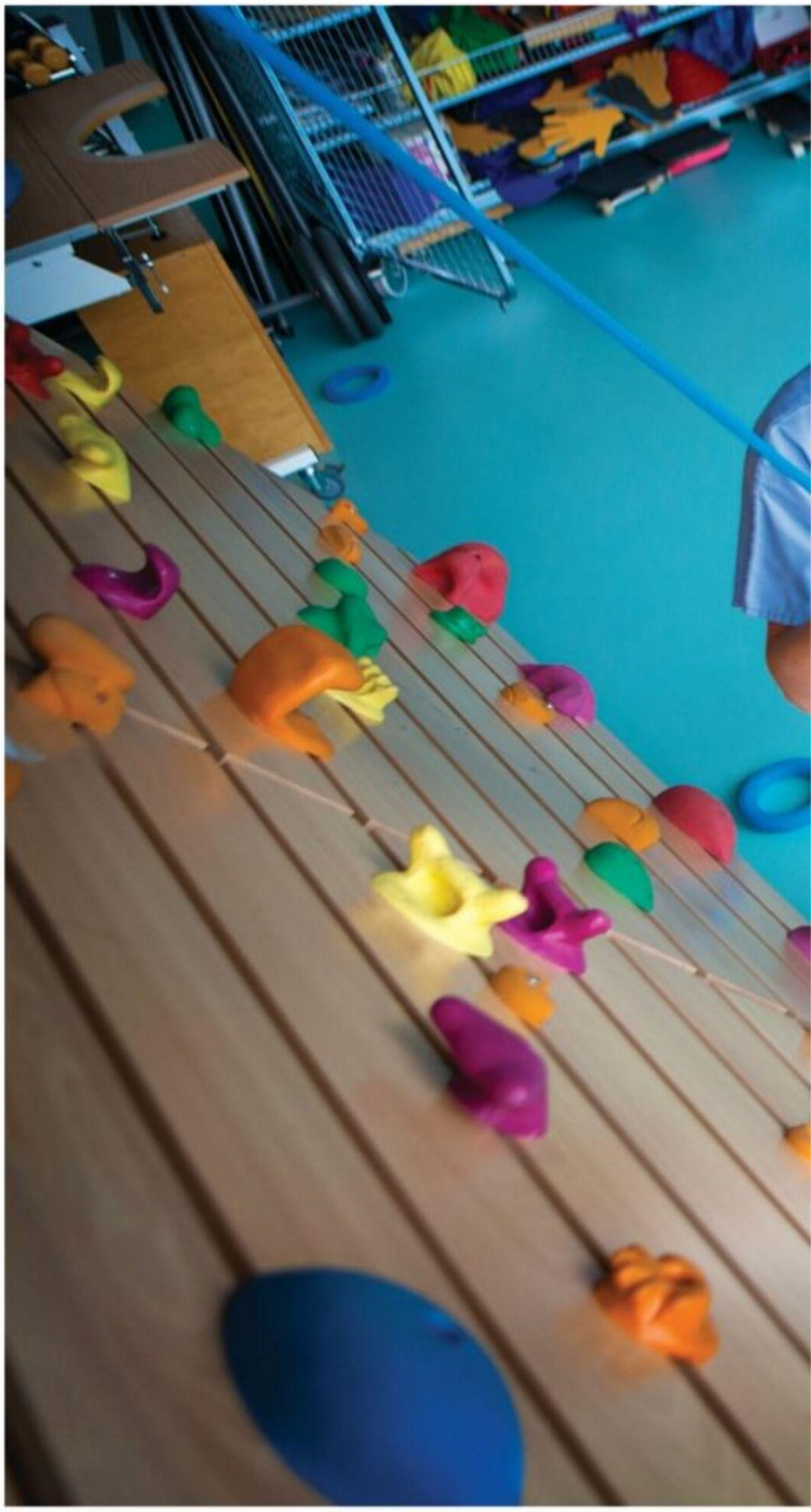
Another avenue for autism detection is chromosomal microarray analysis (CMA), which looks for known genetic anomalies that have been linked to autism. There are dozens of genetic syndromes correlated to autism. For example, Fragile X syndrome results from a defective gene on the X chromosome. It can cause intellectual disabilities and epilepsy, and it mostly affects boys. Rett syndrome, which disrupts brain development, leads to progressive loss of motor skills and language and primarily affects girls. Angelman syndrome is equally found in boys and girls. It causes mental disability and delayed development, as well as difficulties relating to balance and speech, and can bring on seizures. And those with Down syndrome have a high likelihood (16 to 18 percent) of also having autism. In addition, researchers have discovered hundreds of other genes that appear to play a part in autism, particularly for level 2 and level 3 individuals.

While research using biometrics and genetics to diagnose autism and its subtypes shows promise, for now, most autistic children and adults are being diagnosed using tools like the ADOS. But it often misses the signs of autism in girls, who make up about one out of every four diagnoses. Culture and assumptions about gender may play a part in the underdiagnosis, with caregivers, teachers, and even clinicians sometimes dismissing autistic behavior in girls as mere shyness.

Autism diagnoses are also rarer in rural and minority communities, where trained diagnosticians are in short supply and autism is often mischaracterized as a behavioral issue or personality disorder. Because of this, in 2015, Kristin Sohl, MD, a professor of pediatrics at the University of Missouri School of Medicine, launched ECHO (Extension for Community Healthcare Outcomes) Autism, a virtual learning platform designed to connect primary care providers in underserved communities with clinical experts. Every ECHO Autism learning community includes an autistic adult or caregiver. So far, the platform has trained 80 primary care physicians in Missouri, and it has set up learning cohorts in five other states.

EARLY INTERVENTION AND TREATMENT

Pierce believes that early diagnosis is critical for the different levels of autism because so many neurological pathways are formed before age 3. "Kids are born with way more connections, called synapses, between neurons than they're going to end up with as adults. There's this process called pruning that happens during the first years of life as really good connections are being formed and less useful connections are pruned away," she explains. Studies have shown that autistic children have more brain cells than their neurotypical peers, and thus more connections. Pierce believes this is a key to understanding autism: It indicates that autistic children's brains aren't pruning cells and forming neural pathways as effectively. If children can be diagnosed early, the hope is that therapies can be created to help them develop more effective neurological connections. "One day, we may even be able to use biotherapeutics to address early brain overgrowth for the more severe types of autism," she says.



For now, the most widely used therapy for autism is applied behavior analysis (ABA). The therapy derives from the work of psychologist B.F. Skinner and seeks to change behavior with carefully repeated drills and rewards. ABA helps kids learn social, academic, motor dexterity, and hygiene skills while offering positive reinforcement. When a change occurs, the child receives praise or a reward that they value. This can be a toy, a chance to watch a video they like, or extra chances to play. Over time, the therapy promotes positive change while reducing negative behaviors, such as self-injury.

ABA is not without its critics, though. In its earliest incarnation, ABA focused on trying to make autistic children behave like neurotypical children by forcing them to engage in prolonged eye contact and repeat assigned tasks. "ABA has given us a structure that can be super helpful, but the old-style ABA was too focused on repetition, and it's not necessary," says Lord, who has determined that it is both developmentally inappropriate and, for many people with autism, harmful. She notes that today's ABA focuses more on parent and child–directed play to improve communication and social interaction. "There's a recognition now that ABA shouldn't

Sylvain exercises weekly with a physiotherapist. Exercise has been shown to improve physical, motor, and social skills.

be used to make autistic people indistinguishable from neurotypical people," Lord says. "Instead, we should ask, 'What is a reasonable goal, and what do you need to do to make that happen?'"

Individualized approaches can take many forms, including combining ABA with other forms of intervention, such as occupational and speech therapy. People with autism often relate better to animals than humans, and animal-assisted interventions (AAI) with rabbits, dogs, guinea pigs, llamas, and other animals have been proven successful.

One widely used AAI is equine therapy. The desire to spend time grooming, feeding, leading, saddling, and riding a horse encourages training and focus and can bring on positive behaviors. A number of studies have likewise shown that the rhythmic movement during horseback riding can result in improved coordination of eye movements, posture, and equilibrium. This can enhance a person's speech, as well as their ability to learn. Therapy with donkeys, which are smaller and have a gentler temperament than horses, has also been shown to be helpful.

Modifying behavior is especially necessary with

Dylan Dyke with Nibbles (left) and Bill, his emotional support ducks. Those with autism can find support animals soothing.

At a shelter for abandoned animals, the creatures are trained to interact with neuroatypical people so the humans and the animals can comfort one another.

those prone to self-injury. For Judith Ursitti, the president of Profound Autism Alliance, her adult son Jack's inability to communicate is especially concerning. Jack, 21, loves music, swimming, and all sorts of transportation, but he can become frustrated when he feels sick or hungry and is unable to communicate those needs to those around him. As with many profoundly autistic adults, Jack's frustration can result in him hurting himself.

"His high support needs are not intermittent. They're constant," Ursitti says. "I would love to be able to leave him alone, but I can't, not without risking him engaging in really severe self-injury." How severe? Jack is currently undergoing intensive behavioral therapy and medical treatment to dissuade him from biting his tongue. He has already bitten off 25 percent of it. If he bites off any more, he will have to be placed on a feeding tube.

With rising rates of autism—a sign of better and increased screenings, heightened general awareness of the condition, and improved collection of data on cases—research and treatment have proven essential to help those with the neurological disorder. "I like to think about the things that we would measure earlier in life as giving us a richer perspective on who this person is currently and who this person is likely to be," says McPartland. "Then we can think about how to provide this person with the best tools, so they can live the kind of life that they're going to want to lead."

Because autism does not go away once someone becomes an adult, Sohl's research has allowed her to stay in touch with her subjects for decades. "My oldest patient is now 31, which, as a pediatrician, was not something I had pictured, but it's amazing," she says. "It's like these snapshots: I get to see the ebbs and flows of their lives, the ups and downs. I get to see the beauty of the diversity within the spectrum."

Jane Nizam looks back on her son's diagnosis using the Autism Diagnostic Observation Schedule and his treatment journey with applied behavioral analysis as a "critical step forward" toward helping their son reach his potential. "The diagnosis process can be emotional and at times frustrating," she says, but it "opens the door to resources, services, and a deeper understanding of how to support your child."

The Nizams' son is a funny, happy, social 5-year-old with a love for math and clocks who attended a specialized preschool run by the Southwest Autism Research and Resource Center in Phoenix. "He's come a long way," Amir says proudly. ◻

A Fight over Autism's Cause

Researchers question Robert F. Kennedy Jr.'s claims that he will find the cause of the disorder by the fall.

BY JEFFREY KLUGER

On its face, the report issued in April by the U.S. Centers for Disease Control and Prevention (CDC) was nothing short of alarming. According to a nationwide survey conducted in 2022 across 16 localities in the United States, 1 in 31 children studied had been diagnosed with autism. That's a significant increase from the 1 in 36 reported in 2020, and a huge jump from 1 in 150 in 2000.

"The autism epidemic is running rampant," declared Robert F. Kennedy Jr., secretary of the Department of Health and Human Services (HHS), in a press release. "President Trump has tasked me with identifying the root causes of the childhood chronic disease epidemic—including autism. We are assembling teams of world-class scientists to focus research on the origins of the epidemic, and we expect to begin to have answers by September."

But Kennedy, who has long embraced a scientifically discredited belief that there is a link between vaccines and autism, has it wrong, say critics—and even the CDC itself. The increases seen in various communities, says the report, "might be due to differences in availability of services for early detection and evaluation and diagnostic practices.... Another reason for differences in prevalence could be whether children have insurance coverage or meet eligibility criteria for access to early intervention services."

That is in keeping with the position of experts, who have maintained for years that increases in autism cases are a mere function of better screening and a widening of the diagnostic criteria of what constitutes the condition. If you look for more autism—and, not insignificantly, have a better understanding of the signs—you're going to find more.

"Most of the rise in autism is not a true rise of autism but an increase in diagnosis and because of changes in diagnostic criteria," says Peter Hotez, MD, PhD, professor of pediatrics and molecular virology at Baylor College of Medicine and director of the Texas Children's Hospital's Center for Vaccine Development. "Also, starting in 2005, the American Academy of Pediatrics asked pediatricians to start

Health and Human Services secretary Robert F. Kennedy Jr. has long touted a scientifically discredited belief linking vaccines and autism.

doing autism screening at between 1 and 2 years of age. Additionally, we've provided more access to autism services, so there's been incentive to get kids help."

Kennedy doesn't agree with that explanation. "One of the things I think we need to move away from today is this ideology that the autism prevalence increases are simply artifacts of better diagnoses, better recognition, or changing diagnostic criteria," he said at a press conference following the release of the CDC report. "Doctors and therapists in the past weren't stupid; they weren't missing all these cases. The epidemic is real." He went on to condemn what he called "epidemic denial" on the part of the scientific community: "External factors, environmental exposures," Kennedy said. "That's where we're going to find the answer."

Among the sources of those exposures Kennedy has cited are environmental and industrial chemicals, food additives, and contaminants in the water supply. What he hasn't mentioned much lately is the widely debunked idea that vaccines cause autism, though that is a drum he has banged repeatedly in the past. It's that history that concerns members of the autism advocacy community. They worry that Kennedy's promise to begin having answers to the causes of autism by September is just a pretext to reach a predetermined conclusion.

"It's become clear that the goal of the administration is to announce that they have found data proving that vaccines cause autism, but not to focus on finding the actual causes," says Alison Singer, the founder of the Autism Science Foundation, which raises funds for autism research, and the mother of an adult daughter with what Singer describes as profound autism. "That question has been asked and answered. There is no link between autism and vaccines. [The risk is that] the administration announces vaccines cause autism and then declares the case closed and stops funding autism research that focuses on finding the actual causes."

Those causes begin with genetics. One 2020 study conducted by Harvard's and MIT's jointly run Broad Institute found 102 genes associated with an increased risk of developing autism. "I imagine that, like me, the many leading companies and academic sites that are focusing on genetically guided treatments for causes of profound autism would find it disquieting that the head of HHS is unaware of the state of the field, in spite of having access to national and international leaders in the field," says Dr. Joseph Buxbaum, PhD, professor of psychiatry, neuro-

A protestor opposed to Kennedy's January nomination as health secretary. Opposite: Studies suggest that prenatal exposure to pesticides might increase the risk of autism.

science, and genetics and genomic sciences at Icahn School of Medicine at Mount Sinai in New York.

That's not to say genes are entirely dispositive; having genes associated with the condition does not mean a child will inevitably develop it. Other factors can come into play. According to one 2022 study, exposure to chemicals such as pesticides and phthalates, as well as air pollution, may awaken sleeping autism genes, as can nutritional deficiencies. That is at least partly in keeping with Kennedy's charge that environmental toxins play a role. Parental age may also be involved, with older mothers and fathers more likely to have an autistic child than younger parents. Hotez cites at least one medication—depakote, an anti-seizure drug—that may also have an autism link if taken by a mother when she is pregnant.

Kennedy, Hotez says, made a "false statement" when he claimed that the scientific community denies that there are any environmental factors at play. "I've said to RFK Jr. that there could be an environmental component, but not vaccines, because autism occurs in fetal brain development well before kids ever see vaccines," Hotez explains.

Paul Offit, MD, director of the Vaccine Education Center at Children's Hospital of Philadelphia and a professor of pediatrics at the University of Pennsylvania's Perelman School of Medicine, also believes that Kennedy's stated goal to begin determining the roots of autism—a condition that has yielded its secrets only slowly over decades of research—by September is nonsense. All of this raises critics' doubts that Kennedy could be anything like a fair and knowledgeable arbiter of the roots of autism—much less that an HHS under his direction could determine those roots in a matter of months.

"When he comes out and says we're going to find the cause of autism by September, it's naive. It's almost childlike, because it's like saying we're going to know the cause of cancer by September," says Hotez. "Everyone knows there are multiple different forms of cancer, there are multiple different forms of autism, multiple different forms of cancer genes, multiple different forms of autism genes. People like myself have spent hours trying to tutor him on all this, and he just doesn't listen." □

The Origins of the Anti-Vaccination Movement

AMERICANS ONCE LARGELY EMBRACED THE MEDICAL TREATMENT, BUT RESISTANCE TO IT HAS BECOME NORMALIZED.

BY HELEN L. MURPHEY

Robert F. Kennedy Jr.'s leadership of the U.S. Department of Health and Human Services has the potential to drastically reshape the public health landscape. Kennedy has long expressed discredited claims, such as that childhood vaccines are linked to autism, and has advocated for a holistic approach to health. His oversight of government agencies including the CDC, NIH, and FDA has raised concern among scientists that he could encourage states to weaken their vaccination requirements.

President Donald Trump's controversial cabinet secretary and the relative popularity of Kennedy's Make America Healthy Again (MAHA) movement speak to a larger mistrust of expert knowledge. Yet they also fall within a longer debate over state power, health, nature, and the body. Distrust of vaccines started long before autism was even described as a clinical syndrome in the 1940s. From its inception, the anti-vaccine movement has been intertwined with a range of political, moral, and spiritual ideas around the rights of the individual versus the community, the limits of governmental power over bodily autonomy, faith in medical expertise, and institutional knowledge.

In the early to mid 19th century, most Americans welcomed vaccines against smallpox. Cowpox-based smallpox vaccines, which drastically improved upon riskier live smallpox inoculations, were first trialed in the United States in 1800 and were quickly embraced by such prominent figures as Thomas Jefferson and James Madison. Under Madison, an "Act to Encourage Vaccination" was passed in 1813, and it provided for distribution of vaccines by mail. In newspaper coverage, vaccination was frequently represented as a measure of progress and enlightenment.

The efficacy of vaccines prompted some states to take a heavier hand in trying to eradicate the disease. In 1855, Massachusetts became the first state to mandate smallpox vaccination for children enrolled in public schools. By the early 1900s, several other states had adopted similar policies. Given the devastatingly high mortality rates associated with smallpox, these laws were justified as measures to protect the general welfare.

While smallpox vaccines had previously garnered pockets of local resistance as alternative medical practices became more popular, the implementation of mandates intensified the opposition by giving it a new focus. Inspired by British activism over the same issue, the Anti-Vaccination Society of America formed in 1879. The organization adopted a twofold strategy that includes advocacy for alternative remedies, such as homeopathy and naturopathy, and legal challenges to mandates.

A particularly far-reaching law escalated the matter to the U.S. Supreme Court. In 1902, the city of Cambridge, Massachsetts, made the smallpox vaccine obligatory for all municipal residents; if a resident refused, they would incur a $5 penalty. In response, a minister

named Henning Jacobson legally challenged his fine by arguing it was unconstitutional. Jacobson claimed that "compulsion to introduce disease into a healthy system is a violation of liberty."

Like the anti-vaccine movement in Great Britain, this strategy of resistance to the smallpox vaccine relied heavily on liberal fears over government intrusion into private matters such as personal health and childrearing. Alfred Milnes, a prominent British anti-vaccination advocate, maintained that even if he could not convince his audience that vaccinations were ineffective, he hoped to win them over on the merits of personal liberty. Similarly, Jacobson argued that Cambridge's vaccine mandate threatened his rights as an individual.

The Supreme Court disagreed. In a 7–2 decision, the justices upheld the law as a matter of self-defense, reasoning that restrictions on individuals can be justified for the public health of the community. Smallpox, a disease with a 30 percent fatality rate that can leave survivors with severe scarring, qualified.

Yet such anti-vaccine justifications had found fertile ground in turn-of-the-century America among proponents of alternative healing who mistrusted mainstream medical expertise. Immanuel Pfeiffer, an opponent to Boston's vaccination laws, wrote in *Our Home Rights*, a Massachusetts-based periodical, that the right to resist tyranny was "inalienable" and mounted a passionate defense of individual bodily autonomy. In his view, protesting such an injustice was not just a right but a duty. While vaccinating oneself and one's family was an individual choice, he granted, forcing others to undergo vaccination was not. He argued that if vaccines were truly effective, then the unvaccinated would be dangerous only to themselves. (In fact, unvaccinated people can be dangerous to those who are immunocompromised or unable to receive a vaccine.)

Others in the anti-vaccine movement focused on the purported inefficacy of the smallpox vaccine. In one of his milder invectives, Pfeiffer compared vaccination to "charms" or "witchcraft," arguing instead that poor hygiene and sanitation caused smallpox—as well as diphtheria and cholera—to fester. This critique linked to broader Progressive-era policies that sought to improve sanitation measures.

At the same time, anti-vaccination movements represented a reaction against Progressive successes in increasing government control over public health. By the turn of the century, there was strong support for greater standardization of medical education and licensing; the American Medical Association solidified its role as the representative of an increasingly professionalized medical orthodoxy. Vaccine resistance, in turn, was particularly pronounced among alternative health practitioners like Reuben Swinburne Clymer, who lamented how despotic doctors overrode the objections of ordinary citizens. Other articles in *Our Home Rights* protested that increased regulation over medicine had led to the prosecution of those practicing medicine without a license.

Moreover, Clymer suggested that vaccines were not just ineffective but dangerous. He argued (contrary to evidence) in a 1901 issue of *Our Home Rights* that vaccinations were hazardous to human vitality and could cause death, particularly among the already vulnerable.

Instead, Pfeiffer and Clymer championed self-healing. Both were involved in the New Thought Movement, a 19th-century spiritual movement that emphasized metaphysics and portrayed disease as an error of thought. Consequently, a holistic and healthy lifestyle in harmony with God would cure all ills. Healing must be either mental or "natural." *Our Home Rights* had a botanic medicine department that promoted herbal and botanical remedies, juxtaposing cures that came from nature with an alienated medical profession. Premised on a view of the human body as a holistic microcosm of a pristine natural world, healing resulted from internal development instead of external injection.

As mainstream medical opinion crystallized in favor of vaccination, the combination of liberal political values, holistic ideas about the body, and alternative health entrepreneurship shaped vaccine resistance after the Jacobson ruling. While the movement failed to discredit vaccination to the government or the scientific establishment, it achieved more modest gains, as many states began to allow for conscientious objection, limiting the compulsory element of the mandates.

Today, the political and legal system could move beyond merely accommodating conscientious objectors; it could introduce barriers to vaccine development or influence state policy to encourage vaccine refusal. This is not isolated to Robert F. Kennedy Jr. The novel factor is rather how anti-vaccine ideas have become relatively normalized through much of the Republican party leadership and will likely shape policy to an unprecedented extent.

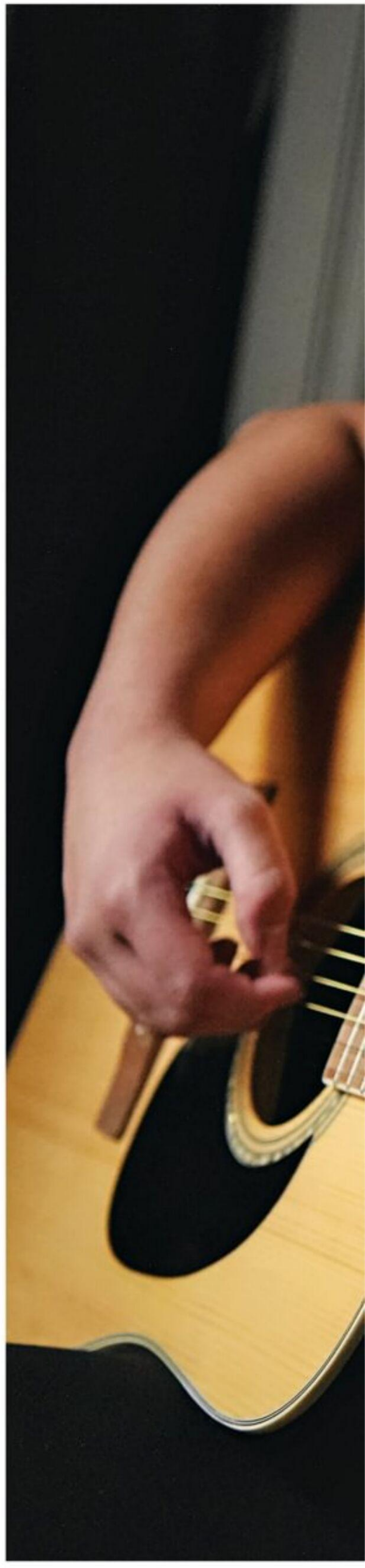
The turn-of-the-century resistance to the smallpox vaccine shows us that anti-vaccine beliefs do not arise in isolation. Taking these root causes seriously and engaging in dialogue rather than simply debunking anti-vaccine beliefs by themselves is increasingly necessary.

Helen L. Murphey is a postdoctoral scholar at the Mershon Center for International Security Studies at Ohio State University. Her research interests include social movements, populist political culture, and disinformation.

Who Is Being Overlooked?

Black and Latino families with autistic children face particular challenges with diagnosis and access to treatment.

BY AYANA BYRD



WHEN CAMILLE PROCTOR'S SON HIT THE ONE-YEAR mark, she recognized that he was not meeting certain developmental speech milestones. The Detroit mom immediately brought it to the attention of their pediatrician—and her concerns were quickly dismissed. "I was told, 'Boys are slower than girls,'" she says.

Frustrated, but undeterred, Proctor sought another medical opinion. And another. After a year, she met with a genetic doctor. "She referred me to a developmental pediatrician, who we saw the following day," Proctor recalls. They received a diagnosis of autism for her son one year after she first suspected there was an issue.

While Proctor's path to getting her son diagnosed was long and with a number of obstacles, it is not unique. According to a 2020 study by the Washington University School of Medicine—one of the largest U.S. studies to date on the topic—on average, Black children are not diagnosed with autism spectrum disorder until three years after their parents first told a pediatrician about their concerns. For Latino children, diagnosis averages 2.5 years later, and they also are more likely to have severe symptoms at the time of diagnosis compared with white non-Latino children.

Delayed diagnosis is not the only danger that Black and Latino families face. Families of color may struggle to find adequate treatment and strong support communities compared with white families. In a 2018 survey, "'We Had to Keep Pushing': Caregivers' Perspectives on Autism

Teenager Shawn Martinez enjoys playing his guitar in his room after school.

Registered behavior technician Kyshau Lee helps Rain Parker with his applied behavior analysis therapy at Shine Pediatric Therapy in Indianapolis.

Screening and Referral Practices of Black Children in Primary Care" by Washington University's Intellectual and Developmental Disabilities Research Center, 22 female caregivers of Black autistic children described barriers in treatment and screening. Many reported that their pediatricians were dismissive of their concerns or said the child's behavior was the result of poor parenting, and that the doctors held harmful stereotypes about the family's cultural group.

In order to ensure that their children have access to the best available care, Black and Latino parents must become advocates in a way that may look different than the standard literature suggests.

GETTING AN EARLY DIAGNOSIS

For the first time, in 2023, the Centers for Disease Control and Prevention (CDC) announced that Black and Latino children were being diagnosed with autism more frequently than white kids in the United States. About 3.1 percent of Black, Hispanic, and Asian or Pacific Islander children have an autism diagnosis, compared with about 2.4 percent of white children. Many recognize this as proof that fewer children are slipping undiagnosed through medical cracks, as the numbers correlate with improved screening and services. But it is important to note that diagnosis often occurs later for Black and Latino children. While autism can be reliably diagnosed at as young as 2 years of age, most Black children receive their first diagnosis after age 5. For Latino children, it is even later.

"Early diagnosis is critical," says Kristina Lopez, PhD, an associate professor of social work at Arizona State University whose focus is on disparities in early diagnosis and subsequent intervention services among Latino families. She explains that a late diagnosis prevents children from getting needed services and increases the chance that they will be placed in the wrong classrooms in school.

An early diagnosis can also alleviate tensions within a family trying to address a child's needs and behavior. "Parents feel a lot of responsibility and guilt for the struggles that their children face, and early diagnosis can go a long, long way to easing some of that," says Amy Weitlauf, PhD, associate professor of pediatrics at Vanderbilt University Medical Center.

In order to get an earlier diagnosis, parents must be as informed as possible. They should be aware of developmental milestones, a list of which is available online from the CDC. Beyond this, it is also

important to track what your own child is doing. "Put a piece of paper on your counter or on the fridge with a magnet, and when you notice or think of things, write it down," advises Weitlauf. "Take that list to every appointment and talk about your concerns, because within the context of a short visit, it's hard to observe stuff." While knowing your child's behavior alongside expected milestones is critical, it may not be enough. "If you receive pushback, keep moving forward with that doctor, or find a different one," says Lopez.

WHAT TREATMENT PROVIDERS CAN DO

Weitlauf is a clinical psychologist who for 15 years has conducted diagnostic evaluations for children with suspected autism. In 2023, she was a part of a study on the ways Black and multiracial families believe autism care could be improved. The study taught Weitlauf many things. Most important, it showed her how she could be a better practitioner. "Families told us that their experiences are different and their race really matters in a lot of situations, including how they are treated within the [medical] system," she says. "My biggest takeaway was that just because I think I'm listening to a family, it doesn't mean I am conveying that in a way that makes sense to them, or that is respectful to them, or actually hears what they're trying to say." This realization showed her that based on what she hears from patients, she and her team can take deliberate steps to make the visit a safer, more inclusive and respectful process.

THE CASE FOR CULTURALLY SENSITIVE PROGRAMS

In addition to seeking providers who are more sensitive to race-based experiences and bias, it is also necessary to find cultural intervention treatment programs, which are based on characteristics and strengths of a particular culture. These can include testing children with toys that are more culturally specific, or holding programs in a family's home or community center. "It's not about creating separate tools or pathways for Black and multiracial families. It's about being more deliberate about how we include different voices in what we do and the programs we develop," says Weitlauf.

Lopez was a part of a team that formed a program that has been successful throughout various Latino communities and involves telenovelas, or soap operas. "We create a story about a Latino family faced with having a child with autism," she says. "The entire family, including grandparents and aunts, is trying to understand autism. It's very narrative, playful, and dramatic, versus an abstract list of information from the CDC, though it is conveying that same information in a way that is more culturally familiar."

Cultural intervention treatment programs can be found through participating in research studies. Families can sign up for these studies not just as participants, but also to access local support groups. The national advocacy organization Autism Speaks offers an online space that can be helpful in locating both local and national resources.

THE POWER OF COMMUNITY

Beyond finding good treatment providers, it is essential that parents of autistic children become part of a strong community that can offer resources and much-needed support. Yet a January 2023 study found that Black and Latino kids had less access to autism services than white children do. In addition, cultural differences, as well as stark differences in how society perceives Black and brown children compared with white kids, can often lead to frustration for parents in support groups.

Camille Proctor remembers when she first sought out community after her son's diagnosis: "I would go to support groups and be the only Black person. I would ask questions like, 'What's going to happen when he's older if he's approached by the police and still isn't speaking? If he doesn't understand how to yield, he'll get hurt.' And they said the officer would understand he is autistic and act accordingly. That didn't sit well with me." Unable to find a community that spoke to her needs, Proctor began her own. The Color of Autism Foundation launched in 2009 and connects Black families with culturally competent support. It offers a range of free support programs and educational resources.

Today, Proctor's son, whom she struggled to get diagnosed in 2008, is 19. Their biggest challenges, she jokes, are because he is a teenager, not because he's autistic. She credits their life now to the community she was able to create and believes it is the path forward for many Black and Latino families. "The goal is to lessen the isolation so parents can understand how they need to be responsive to their children's needs," she says. ☐

Autism Timeline

It has taken scientists and researchers more than a century to understand the disorder.

BY AVA ERICKSON

1911
Leading Swiss psychiatrist Paul Eugen Bleuler uses the word *autism* to describe the state of insulation from reality or withdrawal within the self in patients he observes. The term comes from the Greek word *autos,* meaning self, and Bleuler links the behavior to schizophrenia.

1910 1915 1920 1925

ONCE MISUNDERSTOOD AND MISdiagnosed, autism has gone from being seen as a rare childhood condition linked to schizophrenia to a well-recognized lifelong neurological disorder with a wide spectrum of varying support needs. The word autism was first used in the early 1900s, but in the century since, the scientific understanding of the condition has advanced greatly. It is now known that autism is an independent condition rather than a symptom of another neurological disorder, that it affects people throughout their life, and that it has a strong genetic component. Society's understanding and acceptance of autism has also grown, and resources for autistic people and their families have become more mainstream.

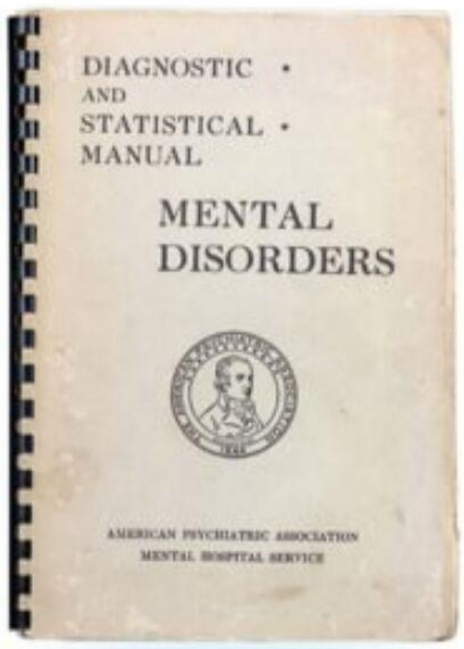
1926
Russian psychiatrist Grunya Sukhareva studies six boys who demonstrate autistic traits. A year later, she expands her research, publishing work regarding autistic pathology in girls. Sukhareva aims to differentiate childhood schizophrenia and autism.

1944
Austrian pediatrician Hans Asperger publishes a study in which he describes a group of children who display autistic traits. He notices that the parents of some children in the study demonstrate similar behaviors, which he posits could mean a genetic link. He also notes the range of ways the condition can present, which will later inform the concept of the autism “spectrum.” It would later be revealed that Asperger collaborated with the Nazis, sending patients to a clinic known for its eugenics program, where nearly 800 were killed.

1930 **1935** **1940** **1945**

1943
Leo Kanner, the “father of child psychiatry” in the United States, publishes a paper describing “early infantile autism” as a distinct clinical syndrome. The 11 children he studies display traits including difficulties with social interaction and changes in routine, good memory, sensitivity to stimuli, echolalia (repeating the words of a speaker), and food allergies.

1949
Kanner posits his “refrigerator mother” theory, which suggests that autism is caused by parents who are cold and detached. Bruno Bettelheim, an Austrian psychologist, would soon expand and popularize the now-discredited theory.



1952
The first edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*) is published. Children who display autistic traits are described as having childhood schizophrenia.

1965
The Sybil Elgar School becomes the first in the world for autistic children after a group of parents recruit Montessori trainee teacher Sybil Elgar to start the school in West London. Elgar's teaching method relies on a structured environment, clear and straightforward communication, and visual aids.

1950 **1955** **1960** **1965**

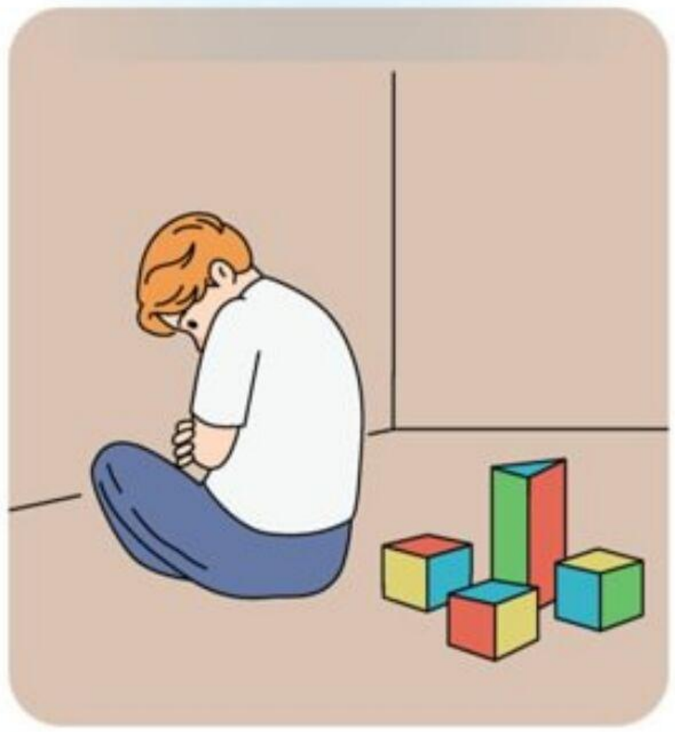
1964
Bernard Rimland, whose son has autism, publishes *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*. His book refutes the refrigerator mother theory, suggesting that autism's cause is rooted in neurological development rather than parenting style.

1965
A group of parents of autistic children have their first meeting. The organization will become the Autism Society—the oldest and largest grassroots autism organization.

ASA
The Voice of Autism.

1966
Researchers estimate that some 1 in 2,500 children have autism.

1973
Ole Ivar Lovaas, a behavioral psychologist at UCLA, conducts his first study on a new type of therapy he had been developing for autistic children: applied behavior analysis. The treatment focuses on positive reinforcement and modeling, and Lovaas notes that the study participants' speech, play, and social skills improve. ABA will become one of the most common autism treatments, though some critics say its emphasis on eliminating behaviors rather than building skills is not productive.



1980
The third edition of the *DSM* establishes autism, which it calls "infantile autism," as an independent disorder separate from childhood schizophrenia and includes criteria for autism diagnosis.

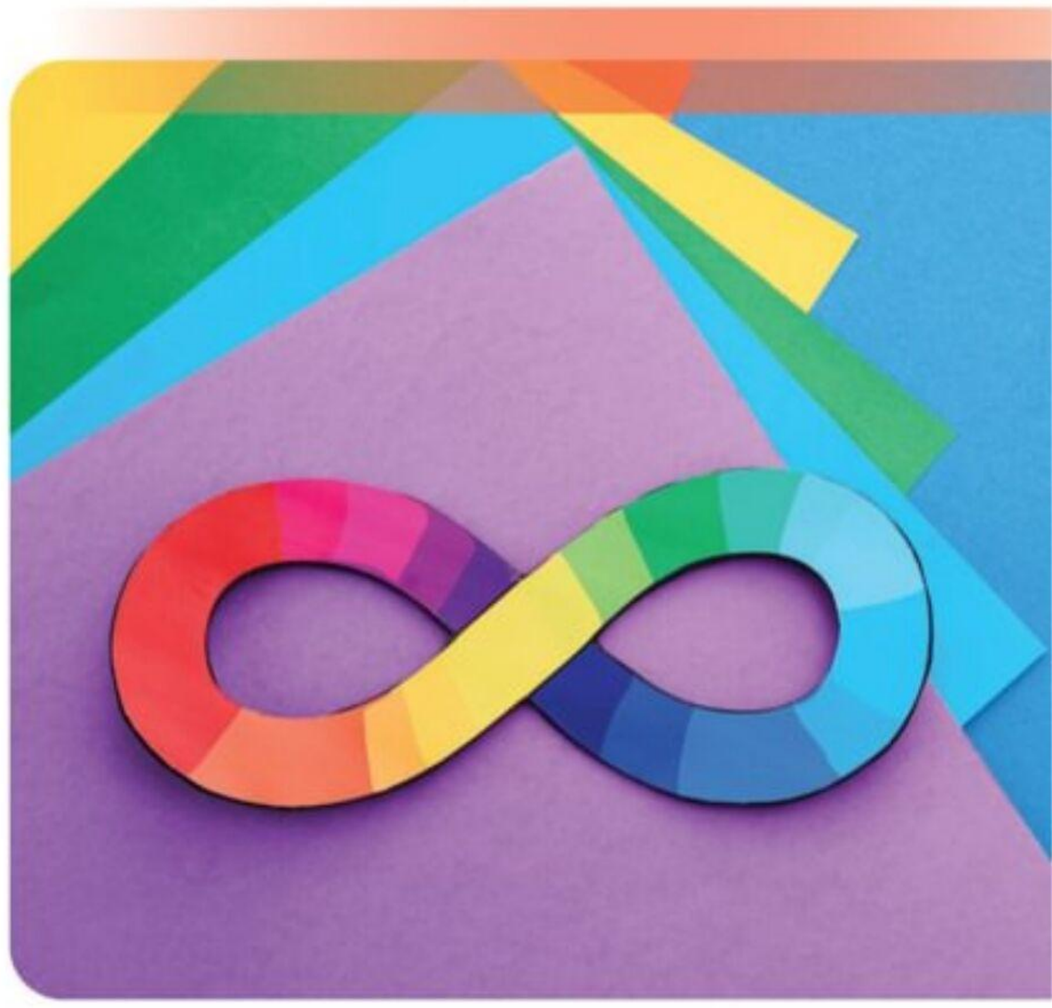
1970 **1975** **1980** **1985**

1979
Psychiatrist Lorna Wing and clinical psychologist Judith Gould introduce the triad of impairments—social interaction, communication, and imagination—that they observe in autistic children in London. They also propose the concept of an autism spectrum.

1981
Building on her pioneering research on the idea that autism is a spectrum, Wing introduces the term Asperger's syndrome. She bases her description on the research of Hans Asperger, introducing the Viennese physician's work to the English-speaking world for the first time.

1987
Autism disorder replaces infantile autism in the *DSM-3-R*, a revised edition of the *DSM-3*, though most of the criteria still centers around childhood diagnosis.

1990
Autism is included as a disability in the Individuals with Disabilities Education Act (IDEA), making it possible for autistic children to get specifc education services such as specialized classroom instruction, speech and occupational therapy, and assistive technology.

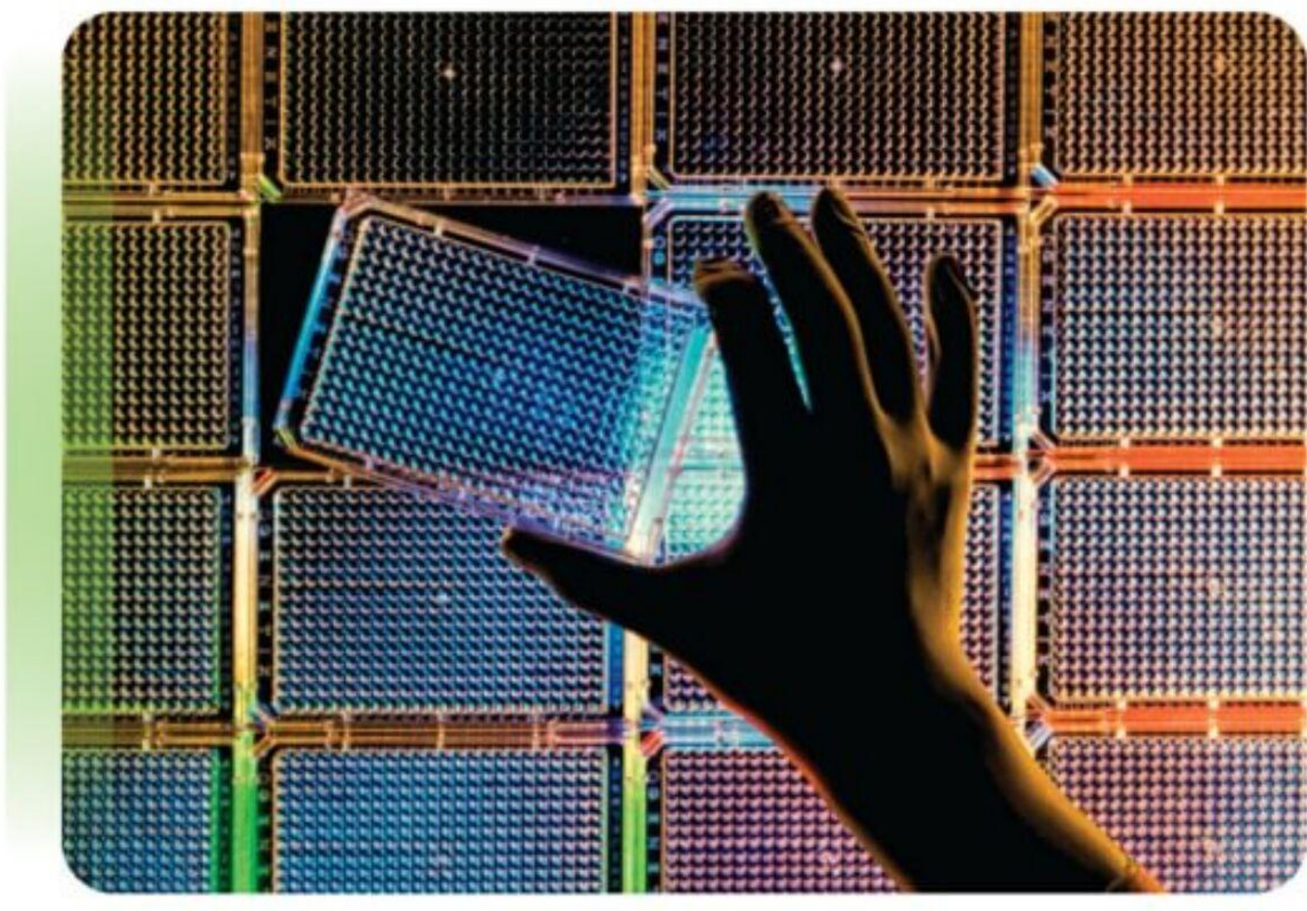


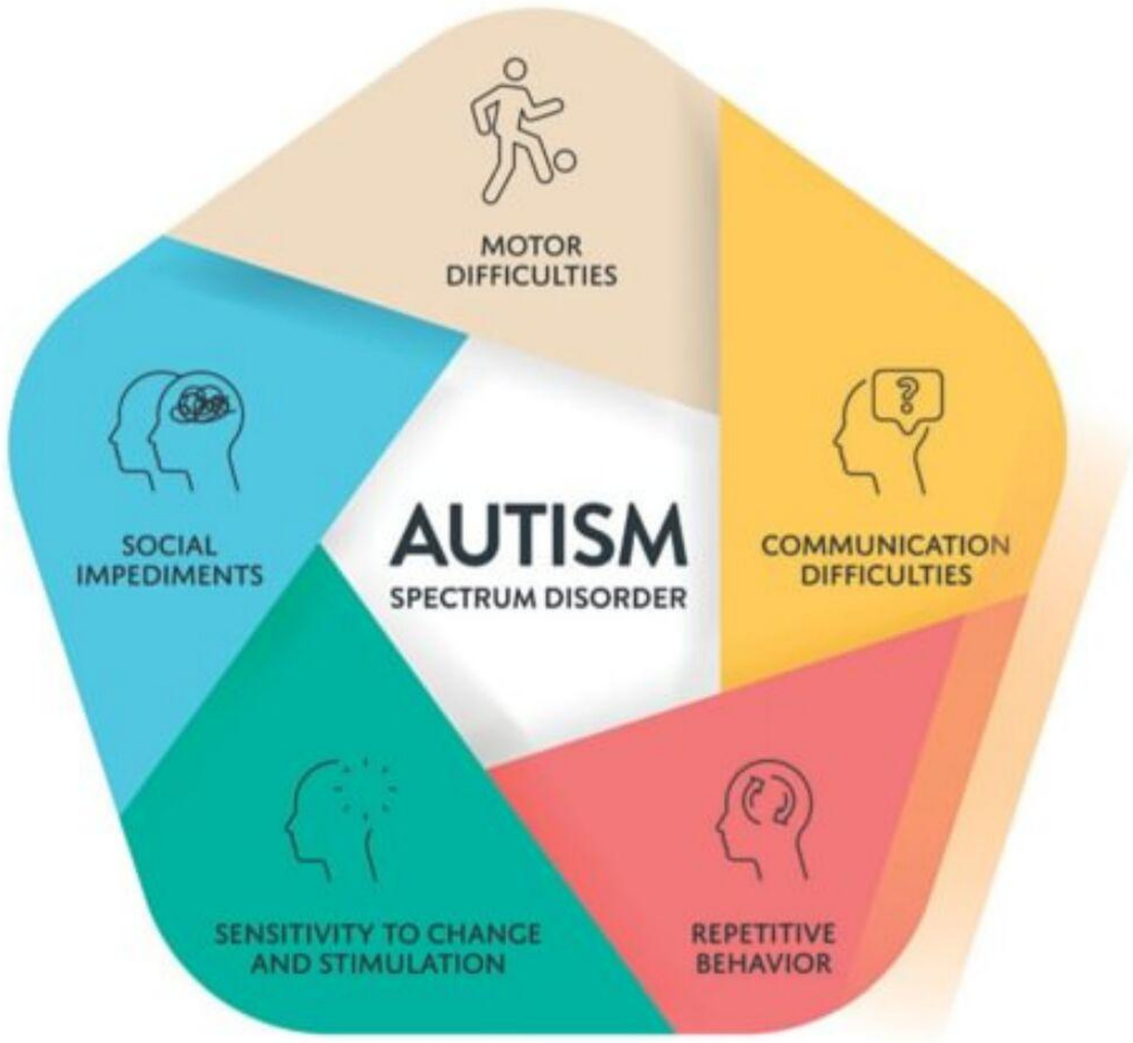
1998
Australian sociologist Judy Singer coins the term neurodiversity to promote the acceptance of the idea that every person's brain is unique.

1990 | **1995** | **2000** | **2005**

1994
The fourth edition of the *DSM* introduces the umbrella term "pervasive developmental disorders," which includes four distinct conditions—Asberger's syndrome, autistic disorder, childhood disintegrative syndrome, and Rett syndrome.

2003
The Human Genome Project, a collaboration that sequences the entire human genome, is completed. Researchers hope to identify the genes that contribute to autism, and though they find hundreds, they can not link any exclusively to autism.





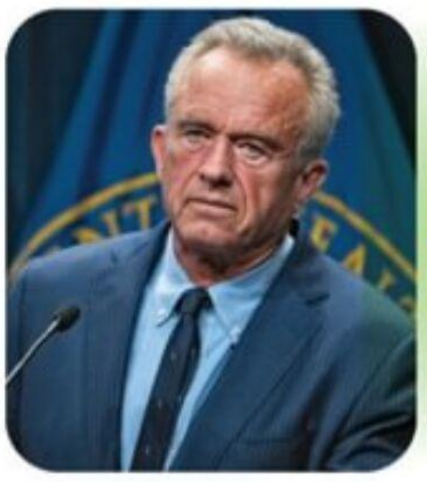
2005
The autism community starts using the rainbow-colored infinity symbol as a way to represent the diversity and inclusion of those on the spectrum.

2013
The *DSM-5* groups autism, Asperger's, and childhood disintegrative disorder into one condition, autism spectrum disorder, which can have varying severity and support needs. The diagnosis is characterized by two features: "persistent impairment in reciprocal social communication and social interaction" and "restricted, repetitive patterns of behavior."

2010 2015 2020 2025

2020
Analyzing the DNA of more than 35,000 people, a National Institutes of Health–funded study identifies variants in 102 genes associated with increased risk of developing autism.

2022
1 in 31 children are diagnosed with autism spectrum disorder.



2025
U.S. Health and Human Services secretary Robert F. Kennedy Jr., who has long championed a discredited claim that vaccines cause autism, announces that he is going to find the disorder's "root causes."

LIVING WITH AUTISM

Ensuring that those on the spectrum receive the support they need to have full and fulfilling lives.

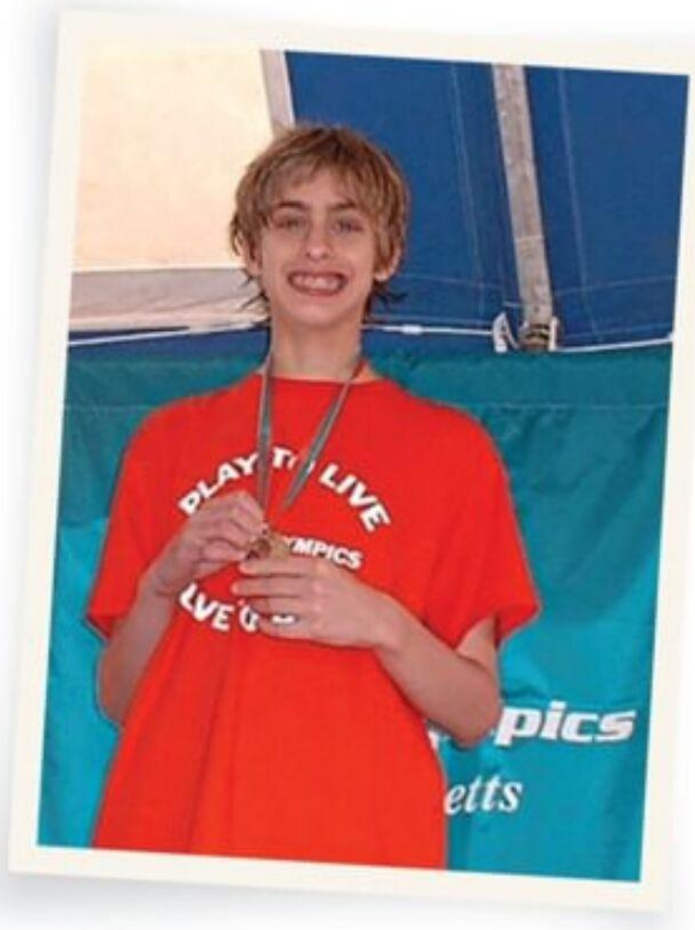
Being Ready for the Gap in Services

The writer tells how "Transition to Adulthood" helped ensure that her son and others were prepared for life as adults with autism.

BY SUSAN SENATOR

TWENTY-ONE YEARS AGO, WHEN MY profoundly autistic son, Nat, turned 14, his school asked us at his Individualized Education Plan (IEP) meeting to consider moving him out of the academic stream and putting him into what they called "pragmatics" studies. No one explained that this was the beginning of Transition to Adulthood, a federally mandated phase in a disabled student's education. These would be Nat's initial steps as he prepared for adulthood and independent living when all supports and services for him ended. He was only a kid—I felt like we were at some dire crossroads, and I'd better not make a mistake. Was I sealing his fate somehow if I let the IEP team make this big change?

Autism families typically describe this period of Transition to Adulthood and out of the school system as a nightmare—something that is completely overwhelming, akin to falling off a cliff. This has not changed all that much since I first dealt with it two decades ago. "Navigating the transition to adulthood for our kids ourselves has been the hardest thing about parenting autism," Susan Goewey, an autism mom from Virginia, recently told me.



Nat has intellectual disabilities, safety skill deficits, and communication, social, and behavioral challenges. By the age of 17, he could no longer safely live with us and had moved out to live at the school residence. When Nat turned 22, the services we got from his school would end, and he'd have to leave that residence. We did not know where he would live. We only knew that there would be funding for him if there was an available slot in a group home.

While at the time it felt overwhelming, it turned out that Nat's team was making the right call for his future.

© 2025 by Susan Senator

The author, a Grateful Dead fan, celebrates her birthday with her son, Nat; opposite, Nat at the Special Olympics.

Above: Antonio Myers attended a 2019 Health and Wellness class, which trains individuals with disabilities to serve as professional support for others. Below: In 2023, kitchen manager Regine Kha (right) assisted Marvin Haquin in preparing meals in a Parisian company's restaurant.

BUILD INDEPENDENT LIVING SKILLS INTO THE EDUCATION PLAN EARLY

Even though most students diagnosed with autism do not have the intensity of needs that someone like Nat has, nonacademic skill-building is a necessity. The earlier a family plans, the better. Unfortunately, many autistic students are not receiving Transition to Adulthood planning soon enough, and they may find they lack the independent living skills they will need in the adult world to hold down a job, attend college, or live on their own. Standardized testing consumes so many learning hours and puts pressure on educators to "teach to the test" rather than teach necessary skills like appropriate behavior on the job, self-care, travel training, personal safety, and advocacy, as illustrated in the article "I Can Identify Saturn, but I Can't Brush My Teeth" in the journal *Education and Training in Autism and Developmental Disabilities*.

Early, regular, and highly individualized transition planning might make the difference between adequate adult skills or none at all. According to Peter Gerhardt, EdD, executive director of the EPIC School in Paramus, New Jersey, "the educational team should consider that anything that you can't do, someone else will have to do for you in adulthood." Even if an autistic student has plans for college, independent-living skill training is a must, given the marked social and behavioral skill deficits typical of the disorder.

> **"The educational team should consider that anything that you can't do, someone else will have to do for you in adulthood."**
>
> —PETER GERHARDT, EDD

BE PREPARED FOR THE GAP IN AUTISM ADULTHOOD SERVICES

Learning the right skills while still in school is one way to prepare for the cliff that is autism adulthood. But how does a student hold on to their school supports when school ends? They will need to find new forms of support, and ways to pay for them. The best time to advocate for that is at those early Transition to Adulthood IEP meetings, all the while keeping in mind that the numbers of autistic people are now estimated by the Centers for Disease Control and Prevention to be 1 in 31, that state budgets have shrunk, and that jobs and day programs with the necessary structure and staffing are few. At the same time, the pandemic and new restrictive policies on immigrants in the workforce have decimated necessary supports and services like group home staffs, personal care attendants, and job coaches.

A 2024 *Disability Health Journal* paper found that, nationwide, only about 40 to 60 percent of adults with intellectual and developmental disabilities were enrolled in Medicaid waiver programs (which enable that population to live in the community), with autistic adults having the lowest enrollments of all. The problem is that demand far exceeds access. Even states like Massachusetts, where Nat lives, while ranked at the top for funding of human services, now have years-long waiting lists for adult autism housing, supports, and programs. "We have close to 2,500 adults in Massachusetts [up from 700 a couple of years ago] waiting for day programming," says Maura Sullivan, CEO of Arc of Massachusetts, part of the nationwide Arc advocacy organization. And housing shortages mean few living options other than the family home.

Considering the challenges autism presents, an isolated life with aging parents could be a formula for disaster. Because of that, autistic students and advocates should familiarize themselves with the organizations they will be dealing with in adulthood—the Administration on Intellectual and Developmental Disabilities (AIDD) and the Rehabilitation Services Administration (RSA)—in order to set themselves up for successful negotiations after age 22. Liaisons from these administrations' state agencies should attend team meetings to aid in the student's transition. This can help bridge the gap between school and service-providing agencies.

UNDERSTAND THE FINANCIAL PARAMETERS OF THE DISABILITY SERVICES SYSTEMS

Once an autistic student has a good idea of their goals for after graduation, they need to get a sense of how to pay for them. Families should start saving money from the earliest days. Autistic students should apply for Supplemental Security

Gideon served customers at Manhattan's Café Joyeux restaurant in 2024. The French chain hires people with autism and Down syndrome.

Income (SSI) and Medicaid—the holy grail of adult resource funding—as soon as possible; Medicaid benefits cover some medical and therapeutic expenses and home- and community-based day services (HCBDS). Students can also open an Achieving a Better Life Experience (ABLE) account or create a special-needs trust without losing their SSI or Medicaid benefits.

To find out what funding is available to autistic adults in your state, start with tried-and-true advocacy organizations like Arc of the United States or the Autism Society of America. Advocacy organizations can also explain legal rights and financial regulations, such as the strict legal limit to how much money a disabled individual on a limited income can have in their name with SSI and Medicaid. If supported housing is a part of an autistic student's vision for adulthood, they should consider getting on waiting lists for the Housing Choice Voucher (HCV) program—also known as Section 8—as soon as possible so they can access low-income housing.

The best way to learn about the adult service system is to reach out to advocacy groups and other autism parents and self-advocates. These are the people who will have the inside scoop and help empower autistic adults to find their voice during Transition to Adulthood and beyond.

DON'T TAKE NO FOR AN ANSWER

Students can start learning about adult program offerings in their very early teens. When Nat was a teenager, one state agency administrator laughed at me when I asked for guidance. But by attending conferences and connecting with families who have been there, I learned what I needed to know.

If the adulthood vision is to live outside of the family home with staff supervision, families and self-advocates will need to build a solid argument at the student's team meetings. When Nat was 17 and had become too aggressive to continue living with us, the team videotaped him for a year to provide evidence of his behavior and got him a placement in the school residence. I recall how I then lived in a state of nauseating panic until just a few months before he turned 22, when a residential housing spot thankfully became available. I'm convinced that this residential placement helped Nat get that support as an adult, although no one on our team would publicly say so.

An autistic student must push hard for their

Autistic students and advocates should familiarize themselves with the organizations they will be dealing with in adulthood.

needs, no matter what type of support they require. College-bound autistic students should know that they will have to advocate for their own accommodations when they leave high school. Similarly, if an autistic student needs a structured, staff-run adult day program, or perhaps a job support, the student should be able to demonstrate and document how they have benefited from structured activities or employment during their school years to persuade the state agencies that this needs to continue to whatever degree possible.

Adult programs vary a lot in offerings, quality, and accommodations. Currently, the low pay rate for staff in day programs discourages well-trained employees from applying for support jobs, so programs may not be willing to handle particularly challenging behaviors. Oanh Thi Thu Bui, a single parent of a newly transitioned 22-year-old, told me, "Currently I only have two days filled for her. She has developed some challenging behaviors for not having access to structured programs." Some families have therefore opted for what is called self-direction, whereby they design their own programming and hire the staff themselves.

The only way to work with the current inadequate adult service delivery system is to start long before your child reaches adulthood, by having IEP goals that emphasize independence, and by understanding the funding mechanisms. Families must be prepared to make the case for supports proactively, and continually. Be that squeaky wheel. Get on those lists. Show up on those radar screens. And the final must-do: Be willing to educate those who later come to you for help. ◻

Susan Senator is a journalist, public speaker, and the author of Autism Adulthood: Insights and Creative Strategies for a Fulfilling Life.

Neurotypical and Neurodiverse

THE PROBLEM WITH LABELS IS THAT SIMPLE LINES CAN'T BE DRAWN BETWEEN DIFFERENCE AND DISABILITY.

BY DAVID BJERKLIE

1998 was a watershed year in autism, and it all started with two new words. The first, *neurodiversity,* was coined by Judy Singer at the University of Technology in Sydney in her undergraduate thesis on the building of autism community. The other word, *neurotypical,* began as part of a satire. Autism activist Laura Tisoncik launched a website she envisioned as a compilation of support and resources for autistic adults. One of the site's features was a fictional research center, the Institute for the Study of the Neurologically Typical (ISNT). "The point of ISNT," said Tisoncik, "was to shine a light on how we are treated." It did so by mocking the "same patronizing, pathologizing voice in which traits commonly held by autistic people are described." The institute offered such insights as "Neurotypical syndrome is a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity." It was a spoof, but one that packed a punch.

It wasn't long, however, before neurodiversity stirred up controversy, especially within the autism community. Again, language was front and center. The words

disability and *disorder* became lightning rods, while many activists insisted the only acceptable word was *difference*. But that didn't capture the experience of countless families. The problem with labels, says Daniella Mini, a writer who has parented a child with autism, is that "they draw a simplistic line between disorder and difference, between undesirable and preferred. When my son was a child, it was generally accepted that curing autism was the goal. Nowadays, many will take issue with the concept of improving, let alone curing, a person's autism. Not everyone agrees on what behaviors we should help our children eliminate and which skills to acquire." She acknowledges that her views have changed over the decades she has parented a child with autism. But she also points out that what made it tougher for her to arrive at her current perspective was the tone of the debate, which suggested, "'You're either with us or against us.' I'm with neither. I'm with both. In my son's case, autism is difference and disability." Mini is quick to add, however, that "I don't doubt that many autistic individuals experience autism as a difference only. Truly, I'm glad these experiences are being voiced and heard, but it's frustrating when the autism-is-never-disability position is generalized."

Writer and autism parent Lisa Pierce Flores concurs. "There's a lot of strange posturing around who gets to be autistic," noting that it can feel exclusionary when, for example, "we are told that our adopted son isn't really autistic because he experienced serious early trauma, both in utero and in infancy, which they contend must be the actual cause of his neurodevelopmental issues. It's as if they believe there is some sort of 'real' autism that stems from genetic or other mysterious factors and is the result of pregnancies where the mother has done nothing wrong. We've also run into people with autistic children who see autism with aggression as a behavioral issue and therefore also not 'really' autism."

The misconceptions are both frustrating and counterproductive, says Pierce Flores. "I think it's also important to acknowledge that comorbidities—for example, my son has type 1 diabetes—can exacerbate the intensity of autism symptoms." (Studies have shown that the vast majority of individuals with autism have at least one co-occurring condition, and roughly half have four or more.) "To pretend there is only one way to be autistic and that everyone's level of need is equal is just another form of marginalization, especially for those with the highest support level needs due to intellectual disability or profound communication challenges," Pierce Flores says.

It can seem that battle lines, once drawn, are impossible to erase. But Simon Baron-Cohen, PhD, director of the Autism Research Center at the University of Cambridge, makes a strong case that it doesn't have to be this way. In a 2019 article in *Scientific American*, Baron-Cohen described the gulf that seems to separate the neurodiversity and medical models of autism. "No wonder this concept is causing such divisions," he wrote. And yet, he argued that the models are not mutually exclusive and can be integrated "by acknowledging that autism contains huge heterogeneity." We can and must make space for both.

Alison Singer, founder of the Autism Science Foundation, agrees. "As in every social movement, contestation and conflict are inevitable…and should come as no surprise," adding the counsel that "we should be patient with each other, however difficult it can be at times, because it is through disputation that we will push boundaries and new pathways forward."

Soon after Morénike Giwa Onaiwu's daughter was diagnosed, Onaiwu discovered that she, too, was autistic. The diagnosis rate of those ages 26 to 34 increased by 450 percent from 2011 to 2022.

A Lifelong Condition

What autistic adults and their families wish others understood.

BY LISA PIERCE FLORES

As a part-time relationship coach at Rutgers University's Center for Adult Autism Services, Amy Gravino spends a lot of her time talking about sex and dating. "Autistic adults are not children in big bodies. That kind of infantilization is so damaging," says Gravino, 42. "This attitude precludes autistic adults from accessing the sexual education they need to navigate dating, relationships, and sexuality safely."

Meanwhile, Jack Ursitti, 21, is a tall and handsome Boston Red Sox fan who loves music and enjoys exploring new sounds and new artists. "He keeps me cool," says his mother, Judith.

Gravino and Ursitti are just two of the estimated 5.4 million U.S. adults with autism. Both will need lifelong support and knowledgeable healthcare providers to help them reach their highest potential. But the nature of those supports is vastly different. Gravino, who was diagnosed at autism level 1 at age 11, went on to earn a master's degree in applied behavioral analysis and is a published author. She was even a finalist for the role dating coach Jennifer Cook ended up landing on *Love on the Spectrum*, the hit Netflix docuseries that has allowed viewers to see that many autistic adults dream of forging romatic relationships.

Yet while Ursitti may have a goofy sense of humor and knows how to make his love of Bruno Mars clear, he can't share any quotes about his favorite artist. Diagnosed at age 2, he is nonverbal, with a

severe intellectual disability. The gap between what Ursitti and Gravino are capable of and what each requires serves as a concise illustration of just how difficult it can be to craft coherent policies and systems to support autistic adults.

ONE SIZE DOES NOT FIT ALL

"I wish the general public knew that autism doesn't just go away when a person becomes an adult," says Zoë Tepper, a student at Arizona State University and member of the Southwest Autism Research and Resource Center's self-advocate advisory board. Tepper is among a growing number of those who serve as consultants to regional and national autism organizations, providing needed insight into what it's like to experience the world through the lens of a neurological condition that can affect everything from sensory processing to communication and impede employment, housing, and other aspects of daily life. As Alison Singer, president of the Autism Science Foundation, notes, "You're an adult a lot longer than you're a kid. There needs to be more recognition that the population is aging and that there is a diversity of needs."

WHAT HAPPENS AFTER SOMEONE AGES OUT

In most states, when people turn 22, they lose access to the patchwork of resources provided by schools and developmental services. This can leave families—even those who went through the federally mandated Transition to Adulthood process and set up plans for employment, postsecondary education, and adult living—scrambing to find sources for funding and support. These can include needed disability payments, housing assistance, and grants from private foundations and Medicaid to cover the cost of healthcare, therapies, and support staff.

In some states, the waiting list for supported housing and other programming can be as long as 10 years. "It's very dependent on where you live," says Judith Ursitti, who cofounded the Profound Autism Alliance. This chronic lack of resources has only increased, especially for the 27 percent of level 3 autistic people like her son Jack, who require 24-7 one-to-one care to maintain safety. "When individuals have very high support needs, when they require one-to-one or two-to-one care, their families are often unable to find service providers to meet their needs," says Desiree Kameka Galloway, the director of the Autism Housing Network (AHN).

GAINING NEEDED SKILLS

At the same time, better understanding and testing for the disorder means that more adults who were thought not to be on the spectrum are now receiving formal diagnoses. "They've always been here," Gravino says. "In the past they were not diagnosed, or they were ignored, but that's not an option anymore."

Not only are they here, but many seek to be accepted, active, and vital members of society. For Andrew Arboe, 31, a three-year transition program after he completed high school proved to be a crucial step in navigating higher education and job training as an autistic adult. After trying out a variety of occupations and working as a job coach for other autistic adults, he decided he needed to work with disabled children. "I wanted to make a difference within the autism community," says

Left: Spencer Russell and his father, Terry, like to listen to music together. Since the Russells cannot afford support staff, Spencer lives at home. Above: Andrew Arboe wanted to help others in the autism community navigate their lives. He has a B.S. in psychology and serves on the advisory board of the Neurodiversity Employment Network.

Arboe, a teacher's aide in Connecticut, who serves on the advisory board for the Neurodiversity Employment Network.

MEDICAL NEEDS

Autistic adults require proper medical care. One group seeking to improve access to treatment is ECHO Autism Communities, a virtual learning platform designed to share autism information with the larger medical community. "We need to change medical education systems to include better training on autism care, including the understanding that autistic adults need mammograms, prostate checks," says ECHO Autism founder Kristin Sohl, MD. "They need to have access to the same lifespan medical care all adults deserve." As she notes, this means better training for medical personnel, law enforcement, and employers: "We have to stop pretending like it's not our job." AHN's Galloway agrees, stressing that community systems need to create policies with the needs of autistic adults in mind. "Autistic people shouldn't always be the ones expected to change and adapt," she says.

A SHORTAGE OF HOUSING

Galloway's organization helps autistic adults find places to live. "Medicaid often fails to provide enough funding to make it possible for beneficiaries to live in group homes or other housing options," she says. "There is not enough money to pay for the trained around-the-clock caregivers required to support them." To compensate for the shortage, AHN has links to more than 300 housing communities and developers. People can search for independent homes or mixed communities that welcome those who are neurodivergent. This is especially

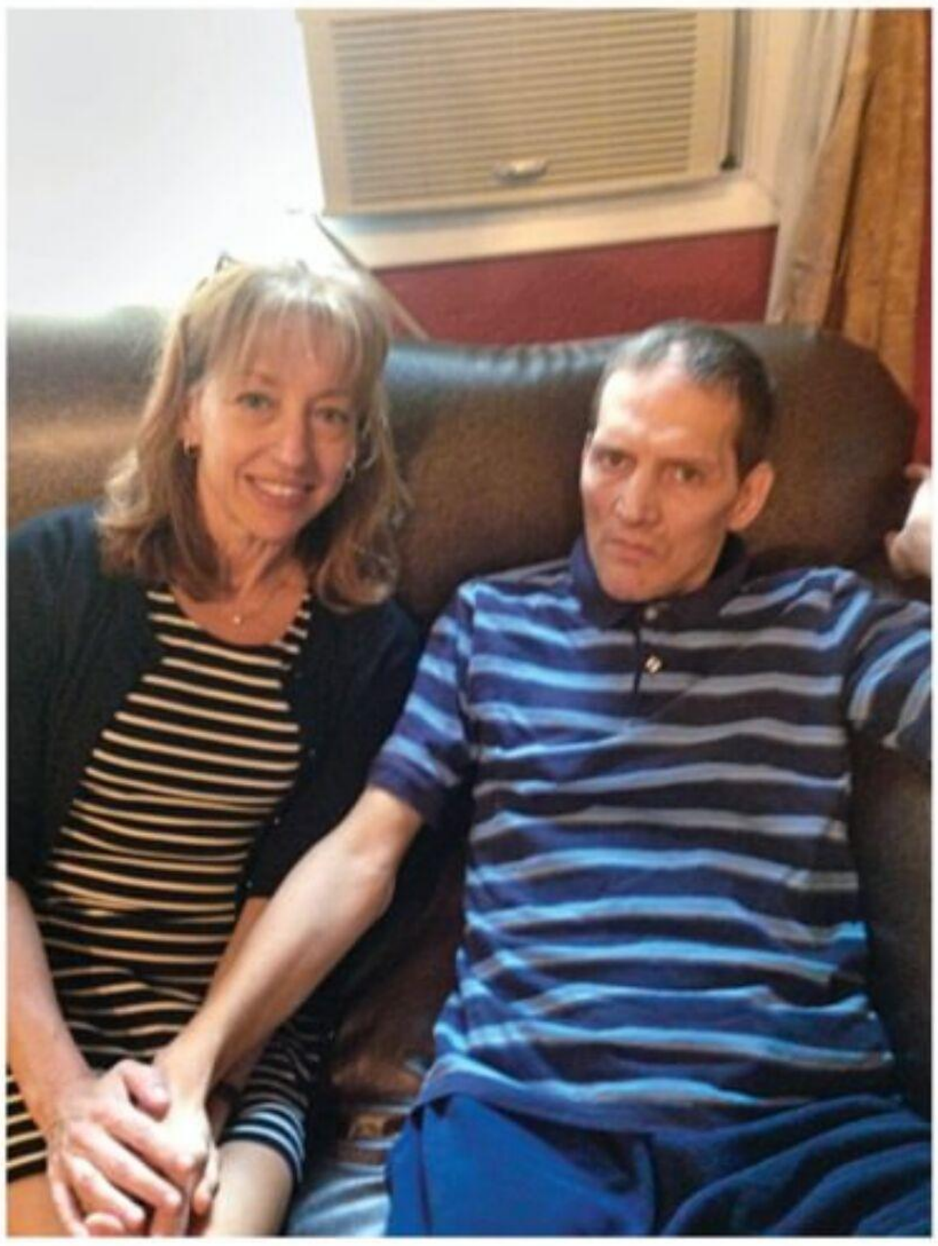
important for those at risk of becoming unhoused when their caregivers get too old or sick to care for them. "When policymakers think about affordable housing, they don't think about autistic adults," Galloway says. "Autistic adults need to have a place to live when their parents can no longer support them. This is a very large population that policymakers are not planning for."

COMING UP WITH UNIQUE SOLUTIONS

The dearth of support leads those who can to make other accomodations. Stand-up comic and podcaster Kirk Smith's autistic son, JJ, is 26. Smith could not find adequate housing for him. "The infrastructure is very thin," he says. Fortunately, JJ's dual Swedish citizenship meant that Smith could find a place for his son in that country's robustly supported housing. "I don't understand, as arguably the richest country in the world by far, why is it so hard to get him services [in the U.S.]?"

Similarly, Singer had to come up with housing solutions for both her daughter, Jodie, 27, and her brother Steven, 61. Each requires 24-7 care. Jodie now lives on a "beautiful, bucolic" working farm in an upstate New York community, one where most of the residents have intellectual disability and are minimally verbal or nonverbal. "She's always loved animals," Singer says of her daughter, "and now she raises animals, so she's very happy."

Steven, who as a child lived at Willowbrook State School—an institution in Staten Island, New York, that was shut down in 1987 following evidence of horrendous patient neglect and abuse—now resides in a group home with five other autistic men. "He delivers Meals on Wheels. He's very active in the community," Singer says, noting how



Alison Singer, president of the Autism Science Foundation, was able to arrange for her brother, Steven (with Singer, above), to live in a group home, while her daughter, Jodie, left, is at the Center for Discovery in New York's Sullivan County.

People with autism have the same hopes as those without. Dani Bowman and Adán Correa went on a few dates on Love on the Spectrum *(here in 2024), but they ended up not pursing a relationship.*

awareness of those with differences has resulted in more acceptance within society. "Kids today are exposed to people with disabilities in a way that they weren't back in the 1960s," she says. "There are many adults with autism, and they are able to have wonderful lives and participate in community activities and social and religious activities. They just need support."

Since services are limited and face cutbacks because of recent changes in federal policy, more of this burden for support will likely shift onto families. Marjorie Partch's minimally verbal autistic brother Stephen, 65, had lived for more than five decades in residential care or group homes. Then, two years ago he contracted COVID-19, lost an alarming amount of weight, and began engaging in unsafe behaviors. So Partch came up with a creative solution. She arranged to have Stephen live with her and to have their sister, Jessica, serve as his paid caregiver. "We're using his benefits in this new way to keep us together," says Partch. "We're riding together again now."

It was the first time the siblings had lived under the same roof since they were children. And after moving in with his sisters, Stephen has started using images and technology to communicate. He's even demonstrated the ability to read, speak, and write the alphabet, skills no one knew he had. Recently, when he began to write his name, he pointed to the paper and said to his sisters, "See, I did it!"

With the change, Partch is happy to note that Stephen is "feeling more secure and more included, and now he's communicating and talking after all these years." □

The Pervasive Loneliness of Autism

The pursuit of independence can deprive autistic people of essential human connection.

BY HARI SRINIVASAN

LONELINESS HAS LONG BEEN A PERVASIVE ISSUE WITHIN the disability community, growing even more pronounced as individuals age. Research indicates that, in particular, adults with autism grapple with markedly higher levels of loneliness than their non-autistic counterparts. Ironically, relentlessly pursuing a disabled person's greatest sign of "success"—independence—might be the very thing that's setting many people with autism on a path toward profound loneliness and fragmented relationships.

The pursuit of self-sufficiency and the coveted ideal of independence are deeply American. But, even if inadvertently, it is fueling disabled individuals' loneliness. In her book *The Beasts of Burden: Animal and Disability Liberation*, disability studies scholar Sunaura Taylor highlights the societal fallout faced by disabled individuals who do not achieve this ideal of independence. Such societal consequences include economic disenfranchisement and social marginalization. But what is not being talked about is that those people who do achieve that type of independence face real costs, too.

Being the optimal version of an adult in America is to move out of your parents' home, live on your own, and build your own family. Within the diverse and vast spectrum of autism, there are undoubtedly those who go on to experience fulfilling relationships and establish families in adulthood. That said, for a good number of others, especially those

who are significantly impacted by social interaction skills, as well as sensory and behavioral challenges, their biological families are likely the only real family they will ever have. But there is a sense of societal disapproval attached to living with your biological family in the U.S. in older age, even if this is a common practice in other cultures. In turn, the societal ideal of independent living for people with autism translates to living apart from their family and being surrounded instead by a series of paid support staff who go home to their own families at the end of each day.

The high turnover in the low-paid and high-stress disability support profession results in fleeting connections, leading to a lack of continuity needed to form lasting relationships. Even the most wonderful of support staff will last a few years at best before they completely disappear from the life of the person with autism.

I've seen this personally. As someone who has autism, I've experienced a revolving door of more than 100 support staff—and I plan on living for many more years. The reality is that any person with autism is a client, a case, a job to the people they tend to interact with most—and that's not the same as family or friends. Higher staff turnover is especially ubiquitous for autistic people who are considered "challenging" cases, as staff naturally look to move to a higher-paying job or an easier case as soon as they can. Consequently, as autistic people age, their world can become increasingly lonely, leaving them even more vulnerable on multiple fronts.

In his book *Together: The Healing Power of Connection in a Sometimes Lonely World*, former U.S. surgeon general Vivek Murthy, MD, eloquently captures the essence of loneliness: the absence of closeness, trust, and genuine affection from friends, loved ones, or community. It is the overwhelming sensation of being "cut off from the people with whom you belong—even if you're surrounded by other people." Murthy also points out the irony in the way that there is an aggressive rush to mitigate and investigate the origins of physical pain even as the emotional pain of loneliness, loss, and disappointment is seen as less consequential; even though overlapping regions in the brain are implicated in both physical and emotional pain.

Autistic individuals face a unique challenge in building trust without the enduring connections to accompany it. It is a misnomer to think that the more significantly impacted autistic people do not want social connection just because they don't or can't verbally communicate their needs. For instance, taking breaks from overwhelming sensory moments should not be conflated with a lack of desire for human connection. As a result, our mental-health needs are also often lost in the melee of other more visible behavioral and health-related challenges that are seen as more pressing. The resulting isolation and loneliness increases the mental health toll, which may manifest as neuropsychiatric behavioral exacerbation, depression, or even apathy.

All humans, disabled or not, yearn for connections that enrich their lives beyond a mere fulfillment of basic needs. The push toward independence in disabled communities, although well intentioned, might inadvertently deprive autistic people of these essential human connections in an otherwise hyper-connected world.

The goal of independence is to empower disabled people to build resilience, develop crucial life skills, and gain a sense of self-worth. Encouraging autonomy fosters confidence and self-assurance, enabling autistics to navigate social situations more effectively. But it's also essential to recognize that advocating for meaningful connections and a more balanced approach to independence does not diminish the importance of autonomy. Striking a balance between independence and support is crucial for the well-being of autistic individuals.

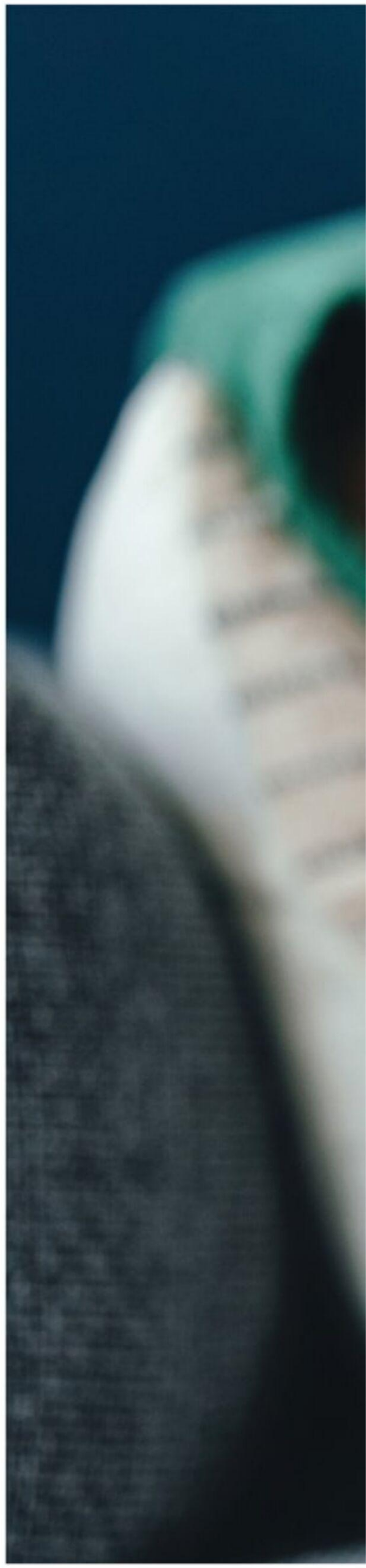
Addressing the loneliness epidemic in the disabled community necessitates a nuanced understanding of independence, because all humans live in a cycle of dependency. The perceived division between independence and dependence is a flawed notion. Embracing this truth could pave the way for a more inclusive society that transcends the limitations of societal norms and helps us build better support systems that result in enduring social connections for people with autism. ☐

Hari Srinivasan is a PhD student in neuroscience at Vanderbilt University, an alum of UC Berkeley, a PD Soros Fellow, a Public Voices Fellow of The OpEd Project, a fellow at the Frist Center for Autism and Innovation, a non-federal member of the NIH's Interagency Autism Coordinating Committee, and on the boards/advisory boards of DREDF, ASAN, ASA, INSAR, Duke Univeristy's ACE, and the Brain Foundation.

A Social Buffer

What people with autism can teach us about mental resilience.

BY TRYSTAN LOUSTAU AND LIANE YOUNG



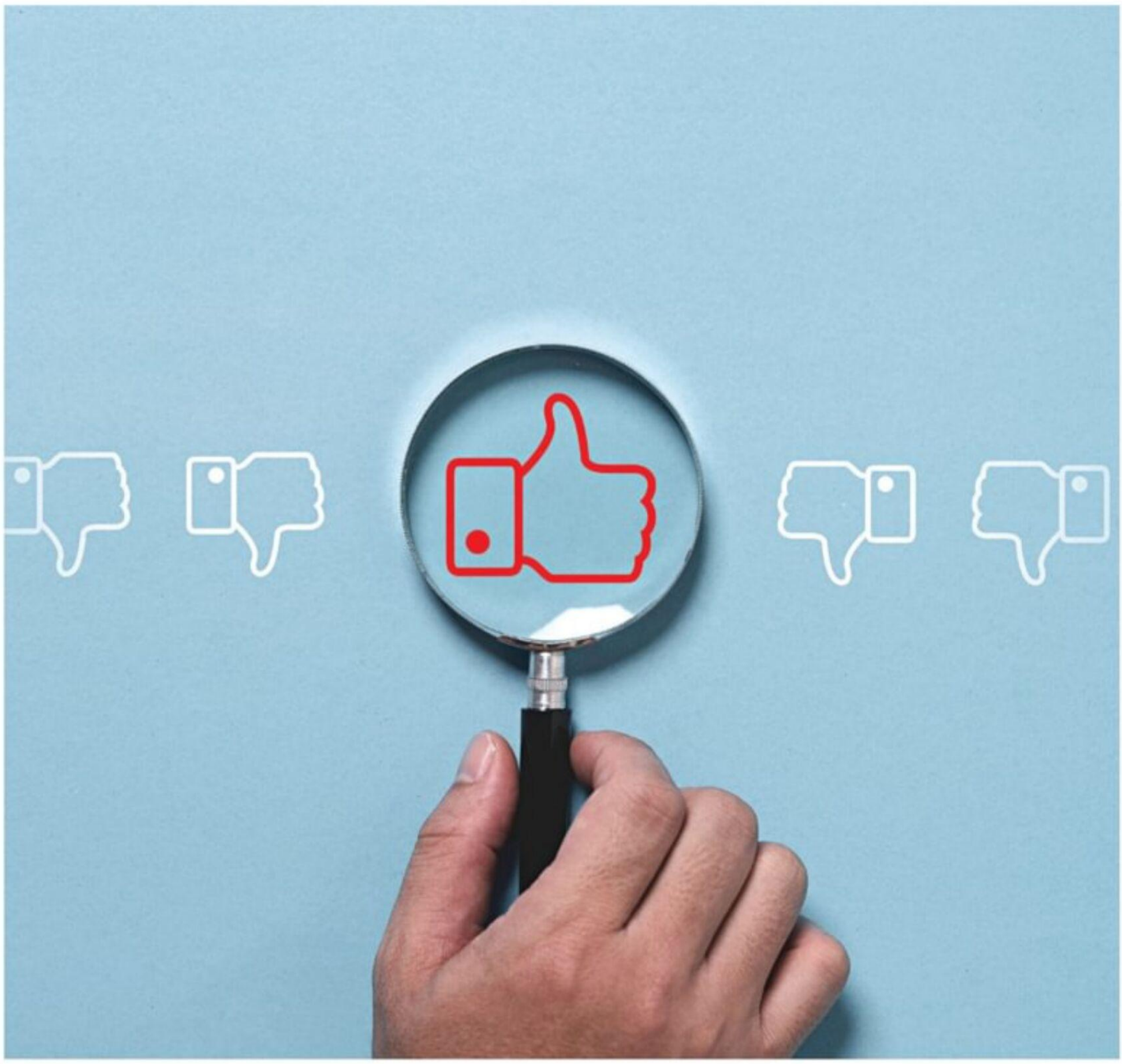
SCROLLING THROUGH SOCIAL MEDIA, WE ARE BOMBARDED by pictures of our friends' vacations and fancy brunches, their career milestones, happy families, and fitness achievements. While we may be happy for them, these social comparisons (evaluations of oneself relative to others) can leave us feeling inadequate and dissatisfied. This may be especially true for young people—recent studies have found that social media use is associated with negative social comparisons—and it leads to reduced well-being, more envy, and greater depressive symptoms. Some scholars, such as social psychologist Jonathan Haidt, PhD, link the detriments of social media and its "poisonous" social comparison to a mental health crisis in adolescents, arguing for a cell phone ban in schools.

Social media is all but unavoidable in many people's lives, and of course, it also has its benefits. This, then, begs the question: Is there a way we can better navigate social media without continuing to incur its possible toll on mental health?

As social scientists who study how people think about and interact with others, we've recently found some promising clues in our research on people with autism. Because autistic people do not process social exchanges in the same way as neurotypical individuals, their responses to social comparison may be a useful guide for the rest of us.

In a series of studies published in August 2024 in the journal *Social*

Autistic and neurotypical individuals express emotions like envy differently.



A study showed that brain regions involved in understanding the mental states of others may function differently in neurodiverse and neurotypical individuals.

Cognition, our research team examined individuals' emotional responses to social comparisons. We compared the degree to which autistic and neurotypical participants expressed social comparison emotions, like envy. Participants in our study read about a hypothetical situation describing a peer who was much better off than the participants—they lived in a nicer house, had more romantic success, and were more accomplished in their career. After reading about this person, participants reported how much envy they felt. Our findings were striking. On average, autistic participants reported 24 percent less envy than neurotypical participants.

So what is it about autism that appears to buffer people against the negative impact of social comparisons? One possible explanation is related to social cognitive differences often observed in autistic individuals. Autistic spectrum disorders are often characterized by difficulties with social communication, reciprocal social interaction, and understanding others' intentions and mental state more generally. Autistic people may be less likely to feel bad after a negative social comparison because they are less likely to consider what is going

on in other people's minds, a psychological process known as perspective taking, or "theory of mind." But why would this reduced attention to the mental state of others protect people with autism from feeling envious or dissatisfied?

It may be that envy is driven not only by seeing what others have but by imagining how happy or satisfied they feel in that given moment. A 2012 study showed that certain brain regions involved in understanding the mental states of others may function differently in autistic individuals than in neurotypical individuals. These differences in neural activity suggest that autistic individuals may rely less on mental state information, which is unobservable and abstract, when processing social interactions and more on tangible, concrete details. In this way, they may be less likely to consider whether others are happier than they are, which could explain why they report feeling less bad in response to social comparisons.

Further supporting this logic, a 2014 study examined responses to social comparison in autistic and neurotypical people using a game in which participants received monetary rewards. The researchers assigned participants to two conditions. In the social comparison condition, participants compared the amount they won to the larger reward of another participant. In the private comparison condition, they compared the amount they won to a larger amount they could have won. While neurotypical participants were much less satisfied with their reward in the social comparison condition, autistic participants' satisfaction did not depend as much on which condition they were in.

Together with our findings, these results point to a critical difference in how social comparisons can be experienced: While some people's happiness depends on whether they compare favorably to others, others focus more on their own outcomes, without factoring in social comparisons. What can this teach us about how to protect ourselves from the potentially damaging effects of social media comparisons on our mental well-being?

While it may be difficult to avoid comparing ourselves to others on social media, the way we respond to these social comparisons is, fortunately, not set in stone. Adopting strategies that shift our focus away from others and onto ourselves (an approach that may come more naturally to autistic people) may help reduce the negative feelings that are linked to adverse mental health outcomes. For instance, keeping a gratitude journal or dedicating our time to hobbies and passions that bring us joy can help us redirect our energy and better appreciate our own lives.

Autistic people may be less likely to feel bad after a negative social comparison because they are less likely to consider what is going on in other people's minds, a psychological process known as perspective taking or "theory of mind."

While social media comparisons may prompt us to think about what we don't have, they can also provide us with new ideas and perspectives, motivating us to improve ourselves and set and accomplish goals. In line with this optimism, a 2018 paper found that while comparisons on Instagram can lead to envy, they can also bring inspiration, underscoring the positive motivational potential of social media.

Although our experiences on social media can lead us to feel like the grass is greener on the other side, we may do well to cultivate a self-improvement mindset and tend to our own emotional landscape and, ultimately, our personal growth. ☐

Trystan Loustau is a PhD student in social psychology at Boston College studying social identity, moral judgment, and intergroup bias. She is a National Science Foundation Graduate Research Fellow and a research consultant for nonprofit organizations, focusing on initiatives that promote social cohesion. Liane Young is a professor of psychology and neuroscience at Boston College and the director of the Morality Lab, which investigates human moral psychology.

PUBLIC AWARENESS

How understanding of autism and those with the disorder has evolved.

BELIEVE IN
YOURSELF
BELIEVE IN
YOURSELF
BELIEVE IN
YOURSELF
PALM BEACH
SCHOOL for AUTISM

Autism in Popular Culture

Media has slowly recognized those on the spectrum and has given artists and writers with autism a chance to be seen and heard.

BY DANIEL S. LEVY

"EIGHTY TWO, 82, 82," OBSERVES RAYMOND BABBITT AS he scans the toothpicks spilled on the diner's floor. His brother Charlie asks "82 what?" to which Raymond monotonously replies, "246 total." The waitress notes that while the box came with 250 toothpicks, four didn't spill out. Curious about his brother's unusual mathematical prowess and how he memorized a large chunk of a phone book overnight, Charlie takes Raymond to see a doctor. "Ray," the doctor asks, "do you know how much the square root of 2,130 is?" He quickly answers: 46.15192304. When the doctor asks Raymond if he is autistic, he slowly responds, "I don't think so. No. Definitely not."

Most moviegoers who flocked to see *Rain Man* in 1988 were like the doctor's nurse, who, when reading Raymond's intake form, asks Charlie, "He's artistic?" When Charlie responds, "No, he's autistic," the nurse looks confused and says, "I'm not familiar with that. What is the exact nature of the problem?" Dustin Hoffman, though, had an understanding of the disorder before he earned the role of Raymond. When he first arrived in New York at the start of his acting career, he worked as an attendant at the New York Psychiatric Institute. And when director Barry Levinson tapped him for the film, he consulted with Temple Grandin, a scientist who used her own experience with autism to create less stressful systems for handling livestock. Hoffman then fashioned a meticulously

In Rain Man, *Raymond Babbitt (Dustin Hoffman) finds it disruptive when the "Walk" sign changes to "Don't Walk." He is then unable to continue crossing the street.*

DONT
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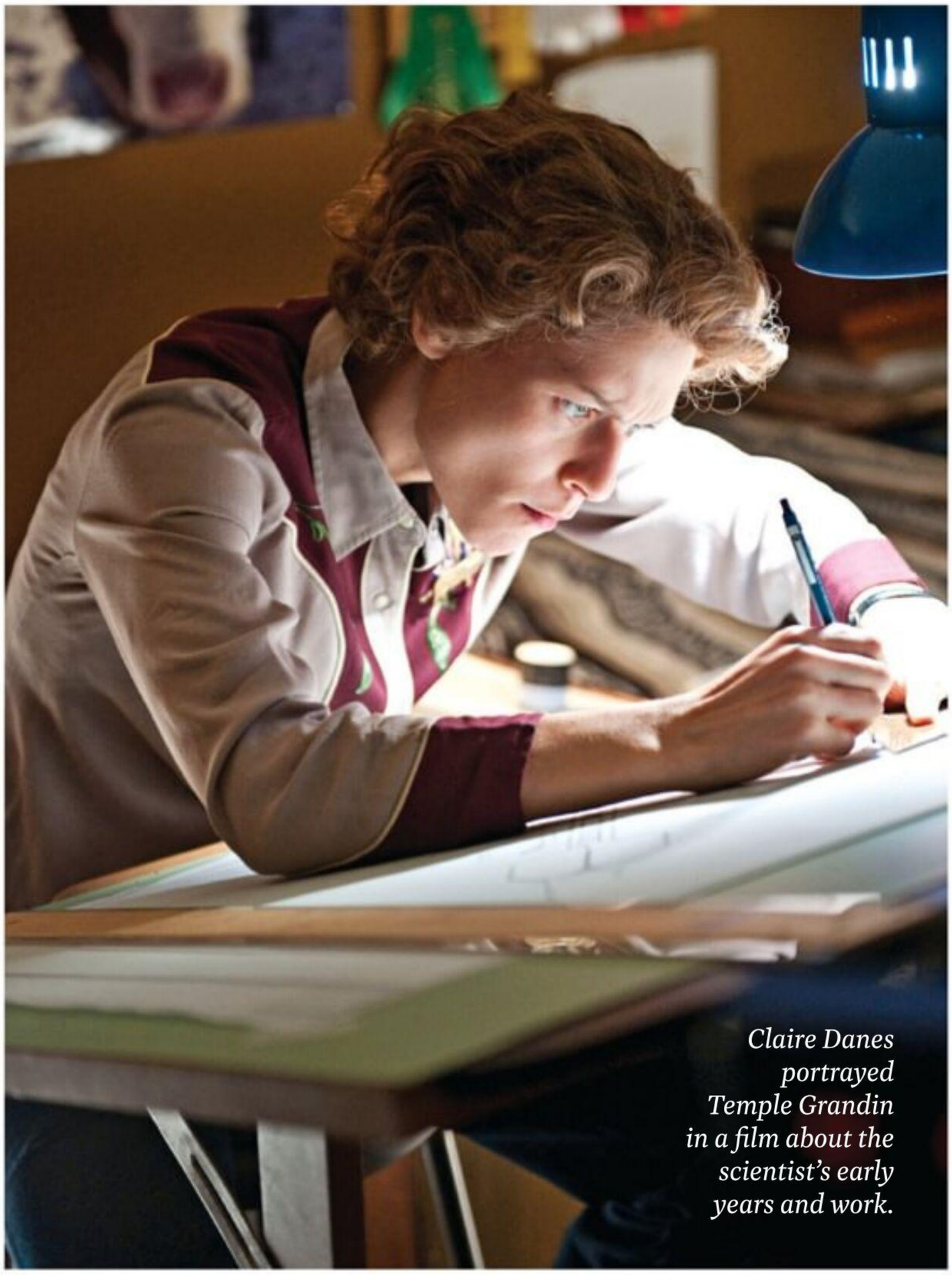
Artie Grape (Leonardo DiCaprio) in What's Eating Gilbert Grape *enjoys repetitive play, such as hiding in a tree alongside his home in Iowa.*

observed performance that embodied Raymond with his vocal stimming, sensitivity to touch, and inability to make eye contact.

Rain Man not only earned Hoffman an Academy Award and the film three more Oscars, including best picture, but it became one of the first times many people became aware of autism. The movie rejected fraudulently uplifting sentiment and in the process increased popular understanding of the neurological disorder. However, it couched those with autism as *Rain Man*–like individuals with eidetic memory and preternatural abilities, though such people are but a small band of people on what we now call the autism spectrum.

Five years later, Leonardo DiCaprio earned an Oscar nomination for his touching turn as Arnie Grape in *What's Eating Gilbert Grape*. The 18-year-old, who has an intellectual disability, is never identified as autistic, but he clearly appears to be. The film further broadened the perception of autism, which back in the early 1990s was still thought to be rare. Similarly, Sean Penn received an Oscar nod for his portrayal of Sam Dawson, an autistic father raising a child played by Dakota Fanning, in 2001's *I Am Sam*. While Hollywood had often featured struggling single dads, it was revelatory for audiences to see one with special needs who lives independently and fights to protect the child he loves.



Claire Danes portrayed Temple Grandin in a film about the scientist's early years and work.

There have since been a flood of films and televsions series about those with autism, from 2009's *Adam* with Hugh Dancy and Rose Byrne to 2018's *Please Stand By* with Fanning as Wendy, a young woman who is fixated on submitting a script for *Star Trek* and speaks fluent Klingon.

Grandin has long championed and written about the rights of autistic individuals, in such books as *Emergence* and *Thinking in Pictures*. Those volumes became the basis for *Temple Grandin*, with Claire Danes playing the socially impaired yet brilliant scientist, who proclaims that she is "different, not less." The 2010 film visually presented Grandin's thought process by showing flashes of images. "That's exactly how I think," she explained to TIME. "It's just like Google for pictures." Grandin, who has a doctorate in animal science, hoped that the film would make others realize "that somebody who is severely autistic really can achieve."

Sheldon Cooper did—at least on TV, earning a Nobel Prize in physics. In the hit 2007–2019 series *The Big Bang Theory,* Cooper is portrayed as being on the spectrum even if it is never explicitly stated, with many seeing his inability to pick up social cues, awkwardness, and obsessive behavior as signs of an autism diagnosis.

In 2022, Netflix aired the Korean show *Extraordinary Attorney Woo* with Park Eun-bin as Woo

Young-woo. She is fixated on dolphins, narwhals, and whales, every kind from blue to humpback, and images of the behemoths occasionally flit by her on the show. Woo wears earmuffs when outside because of her sensitivity to sound and has a rigid need for predictability, such as eating kimbap (seaweed rice rolls) every day. She also has echolalia, repeating "kayak, deed rotator noon, race car," a string of palindromes (words that are spelled the same forward and backward), when she introduces herself. As the show progresses, Woo slowly learns to use rotating doors, is accepted by her neurotypical colleagues, and uses her crackerjack knowledge of the law to win tough cases.

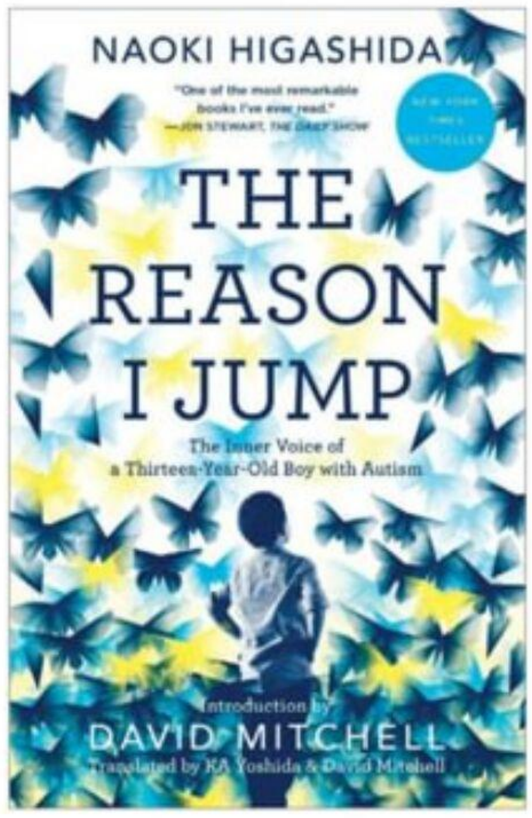
Even shows aimed at children now explore the world of autism. *Sesame Street*, which has a long history of championing differently abled people, consulted with the Autistic Self Advocacy Network and other groups when it sought to create an autistic Muppet. In 2017, it introduced Julia, a bright-eyed, orange-haired girl. Julia flaps her hands, bounces when she is happy, and is sensitive to loud noise. The program depicts her as just one of the many inhabitants on that welcoming street—as its theme song extols, "Everything's A-OK."

And after years of ignoring those in the autistic community, there are now not only movies and shows about autistic people but also programs star-

In Extraordinary Attorney Woo, *Woo Young-woo (Park Eun-bin), above, is hyperfixated on whales. Opposite: Julia (center, with orange hair) is a welcome inhabitant of* Sesame Street.

ring and created by autistic actors and writers, allowing them to speak for themselves and present their lives on screen. Many of these shows have resonated with autistic and non-autistic viewers. In 2013's *Stand Clear of the Closing Doors*, Jesus Sanchez-Velez plays an autistic teen lost in New York City. The TV show *Atypical* is about a young man fascinated by penguins and similarly includes autistic actors and writers. Netflix's 2020 *Love on the Spectrum* is a reality show about the struggles and triumphs of dating, romance, and sex, something most people grapple with. In the process, it reveals the common humanity we all share, as well as the regular challenges autistic people face. And in 2022, on *As We See It*, Emmy-winning *Friday Night Lights* writer Jason Katims—who is the father of an autistic son—created a show that follows three autistic actors, Rick Glassman, Sue Ann Pien, and Albert Rutecki, who play 20-something roommates exploring the joys and frustrations of life.

For younger audiences, the writing and voice cast of 2017's *Pablo* was made up of people with autism. The Irish and British children's show is a combination of live action and animation. The theme song proclaims, "Pablo thinks differently/ Sees the world in different ways," and the 5-year-old uses his art to create animals such as a noise-averse mouse, an energetic orangutan, and a bird


NAOKI HIGASHIDA
"One of the most remarkable books I've ever read."
—JON STEWART, THE DAILY SHOW
THE REASON I JUMP
The Inner Voice of a Thirteen-Year-Old Boy with Autism
Introduction by
DAVID MITCHELL
Translated by KA Yoshida & David Mitchell

Naoki Higashida, who is nonverbal, wrote The Reason I Jump *(above) to help others understand the lives of autistic people. Left: Mickey Rowe was the first autistic actor to play the lead in* The Curious Incident of the Dog in the Night-Time.

that flaps her wings, all characters that represent various facets of the disorder. As creator Gráinne McGuinness says, "It's a movement that seeks to build awareness internationally about what it might be like to see the world from the perspective of someone with autism."

Documentaries have further helped many people better understand the disorder. The cast of 2007's *Autism the Musical* includes autistic children who write and stage a play. There's 2016's *Life Animated,* based on the memoir by Ron Suskind about how his nonverbal son, Owen, relied on Disney films to start to speak and make sense of the world. And *I Am Greta* is a 2020 film that follows the Swedish environmental activist Greta Thunberg, who was diagnosed at level 1.

Books have long been a mainstay for presenting perspectives on the disorder. Mark Haddon's 2003 Whitbread Award–winning *The Curious Incident of the Dog in the Night-Time* is about Christopher John Francis Boone, a 15-year-old English boy who as a latter-day Sherlock Holmes looks into the death of a neighbor's dog, Wellington. When the Tony-winning play based on Haddon's book opened in Indiana, Mickey Rowe became the first autistic actor to play the lead. He then wrote about his experiences in *Fearlessly Different: An Autistic Actor's Journey to Broadway's Biggest Stage*, noting that he acted

Abbey Romeo and David Isaacman met on the reality show Love on the Spectrum *and are now in a long-term relationship.*

"because of and not in spite of my autism.

In his 2007 bestseller *The Reason I Jump*, Naoki Higashida sought to explain the lives of autistic people. Higashida is nonverbal and wrote the memoir when he was 13 by using a Japanese alphabet board. He sets out to answer questions such as "Why do you line up your toys and blocks?" and "Why are you so obsessive about certain things?" Filmmaker Jerry Rothwell then brought out an expressionist take on Higashida's book. The 2020 movie follows five nonspeaking autistic people, visually portraying their sensory experiences. It articulates their inner thoughts and their unseen worlds through impressionistic details, with *Variety* calling the film an "inventive, sensuous documentary."

Helping people understand the thoughts, beliefs, and dreams of those with autism is the aim of the best of these movies, shows, and books. These works present the fullness and value of their lives. As Attorney Woo says when comparing her life to that of a narwhal whale living with a pod of belugas she has seen in a documentary: "I swim in a foreign ocean, and all around me are strange belugas. They're all in a society I can't quite belong to. And certain whales actually despise me. It's all right. I guess that's what my life is like.... I think my life is unusual, peculiar, but it has value. It's a beautiful life." □

Some of the Faces of Autism

Considering that there are more than 75 million people with autism in the world, it's no surprise that a number of prominent people have been diagnosed. Certain symptoms, such as restricted interests or savant syndrome, may even set autistic people up to excel, whether it's in science or entertainment or sports.

BY AVA ERICKSON

Bill Gates

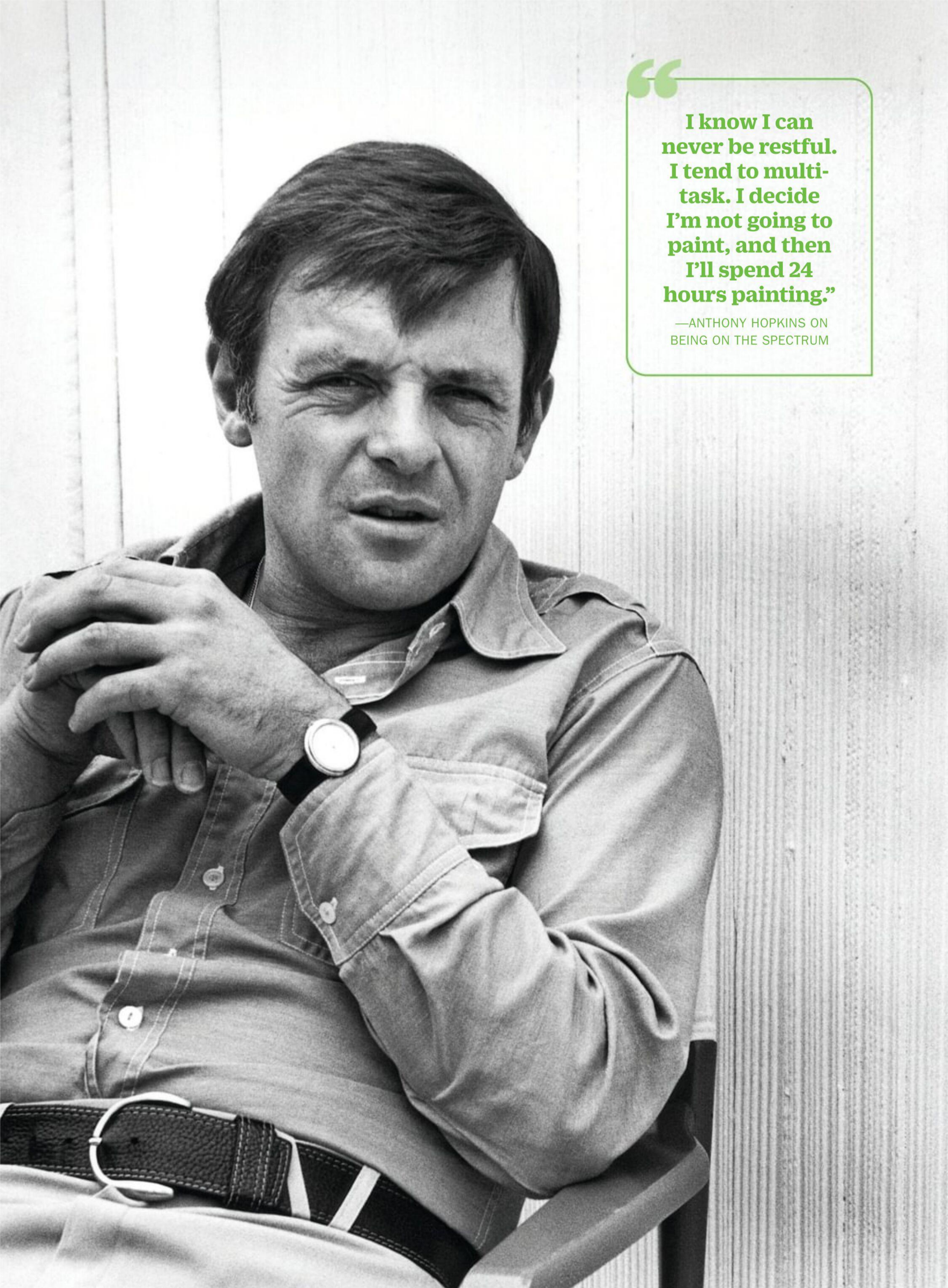
COMPUTER PROGRAMMER

While he was never officially diagnosed, the cofounder of Microsoft revealed in his memoir *Source Code: My Beginnings* that he probably would have been if he were growing up today. Gates always knew he was different, but his intensity was ultimately a benefit. "I didn't behave in a standard way, and yet that deep concentration that got applied to math and science and eventually to all those programming experiences I had, that became a strength," he told the *Wall Street Journal*.

Bella Ramsey

ACTOR

The 21-year-old star of *The Last of Us* only recently discovered they had autism, a diagnosis they told *Vogue* was freeing. "It enables me to walk through the world with more grace toward myself about not being able to do the easy everyday tasks that everyone else seems to be able to do," they said. And for Ramsey, having autism has been advantageous, too. "I've always been watching and learning from people. Having to learn more manually how to socialize and interact with the people around me has helped me with acting."



I know I can never be restful. I tend to multi-task. I decide I'm not going to paint, and then I'll spend 24 hours painting."

—ANTHONY HOPKINS ON BEING ON THE SPECTRUM

Armani Williams

NASCAR DRIVER

The 25-year-old Williams is the first NASCAR driver to openly speak about being on the autism spectrum. "I wanted to prove to everyone that autism can be a strength, not a weakness," he told CNN. Williams's autism comes with a hyperfocus on details, which led him to develop an intense interest in all things automotive, from go-kart racing to auto mechanics. "Every driver has focus, but because I have autism, I have a laser-like focus; you have to almost be the car," he said.

Anthony Hopkins

ACTOR

Oscar-winning actor Hopkins was in his 70s when he was diagnosed with Asperger's, which is now designated as level 1 ASD. As a child, he struggled in school, and he found solace in art and acting. "I didn't know Asperger's even existed," the *Silence of the Lambs* star told Palm Springs, California, newspaper *The Desert Sun* in 2017. "I could never settle anywhere. I was troubled and caused trouble, especially in my early years. I matured a bit, so I'm at much more peace with myself."

Temple Grandin

SCIENTIST

Grandin is known for her 1990s transformation of the meat industry through the design of more humane treatment protocols for livestock. She received an autism diagnosis when she was 3 and struggled to fit in with her peers throughout her life, but her autism ultimately informed her work. "Autism helped me understand animals because I think in pictures. Since animals do not have language, their memories have to be sensory-based instead of word-based," she told *Stanford Medicine News* in 2014. "Animal cognition has similarities to autism cognition. Animals are very aware of small, sensory details in the environment. People on the autism spectrum excel at work involving details."

Greta Thunberg

ENVIRONMENTAL ACTIVIST

The Swedish climate activist went public in 2019 at age 16 about her autism diagnosis after years of being criticized for her appearance and behavior. "When haters go after your looks and differences, it means they have nowhere left to go. And then you know you're winning!" Thunberg wrote in an Instagram post. "I have Asperger's syndrome, and that means I'm sometimes a bit different from the norm. And—given the right circumstances—being different is a superpower."

The diagnosis was almost only positive for me. It helped me get the support I needed and made me understand why I was like this."

—GRETA THUNBERG ON LEARNING THAT SHE IS AUTISTIC

Helen Hoang

NOVELIST

When Hoang wrote *The Kiss Quotient*, which follows the love life of an autistic woman, she had recently been diagnosed and was trying to make sense of what it meant. "The heroine, Stella, deals with a lot of insecurity about herself because she's on the spectrum," Hoang told NPR about how she drew from her own experience to create the book's protagonist. "It was freeing to have her go through that journey, where she confronts this issue and quits being ashamed of it." *The Kiss Quotient* was one of the first romance novels to center on an autistic person, and it earned the Goodreads Choice Award and a place on the *Washington Post*'s "50 notable works of fiction" list in 2018.

Daryl Hannah

ACTOR

As a child, Hannah suffered from debilitating shyness, and at one point doctors even wanted to put her in an institution, though her mother refused. She began pursuing her movie career at age 17, but the *Splash* and *Kill Bill* star often skipped out on talk shows and premieres. Over the years, she learned how to cope with her symptoms by leading a quiet life mostly out of the public eye, living off the grid with her animals. She only began speaking publicly about her autism diagnosis in 2013.

A Mother's Journey

Learning that her young child was "maybe autistic" was the writer's first step in ensuring that he would have a fulfilling life.

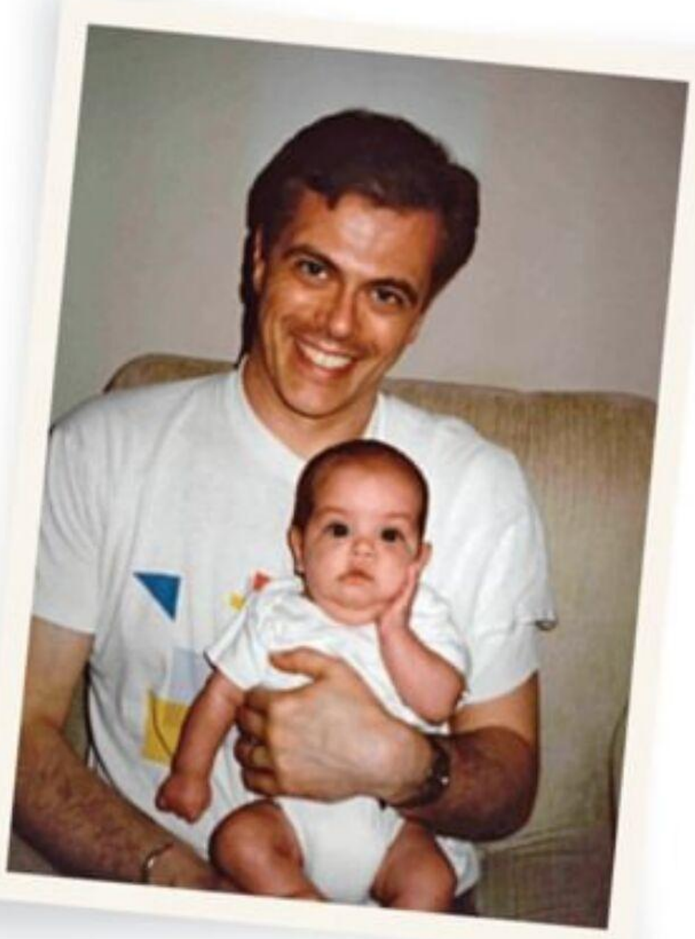
BY AMY LENNARD GOEHNER

"MAYBE AUTISTIC." THOSE WERE the words the psychiatrist quietly said after evaluating our 18-month-old son, Nate. My husband, Fred, and I had scheduled the appointment on the advice of relatives who work with special-needs kids and recognize developmental milestones when a toddler reaches age 1.

Fred and I had navigated a bumpy road to parenthood. There were fertility injections, a varicocelectomy, miscarriage, even an adoption scammer in Syracuse before we finally reached 3-month-old Gustavo, our Nathan "Nate" Gustavo, in Paraguay.

But "maybe autistic"? We had no road map. Later that same day, after I'd stopped crying, I called Barbara, a pediatric speech therapist I'd met socially. She met with the three of us the next day. Nate was nonverbal and zipped around her office like a self-propelled buzz saw. Thankfully, in Barbara we found a guide for what lay ahead. She became the first member of the team of professionals we formed who would help Nate, and us.

We dubbed Barbara our captain, and she quickly hit on Nate's love of music, which she used as the key to unlock his language. I bolstered those lessons every night when I'd sing Nate to sleep. I had no idea that the lyrics were finding their way into Nate's exceptional memory until the day he joined me in singing "Cheek to Cheek." Nate personalizes each song by adding the name of his first crush to the lyrics, so Elvis Presley's "I can't help falling in love with you" became "I can't help falling in love with…Andrea."



Besides his memory, another one of Nate's extraordinary abilities is his hand-eye coordination, which he delightedly puts to use by tossing small

Nate loves trains and likes to go with Amy to his hometown station, a spot he calls "Nate's Happy Place." Opposite: A 3-month-old Nate with dad Fred.

For train-loving Nate, it is always a thrill to ride the New York subway with his brother, Joey, above, or to wait for Joey at the Hudson train station. Left: Nate, 5, and Fred with infant Joey in 1999.

objects like pebbles—and, once, my wedding ring—onto razor-thin ledges. And if that ledge is moving, such as a ceiling fan, he might fling a spoonful of mashed potatoes. "Great shot, Natey!" was the admiring reaction of our host during one Thanksgiving dinner.

Of course, strangers were not always cheering Nate's aberrant behavior, such as when he'd crawl over everyone on the bus to reach his favorite last-row window seat. Because of that, we always needed to know the lay of the land before venturing anywhere, even a new park with a fountain, where Nate might strip and wade in among the toddlers when he was no longer a toddler. Like many Manhattan residents, we didn't own a car, so we traveled out of town by train only to visit family.

Yes, there were challenges, but when Nate was 4, there was only one thing that I felt was missing. "I really want to adopt another baby," I told Fred. "But what if he or she has special needs?" he asked. Well, I answered, "Then we'll be experts!"

A year later, we flew to Florida to welcome 2-day-old Joey. Now, I thought, I had everything—everyone—I'd ever wanted.

But my world changed on a warm June evening 10 weeks later, when Nate was asleep in his room and Joey in a bassinet at the foot of our bed. As Fred lay beside me, he hollered once and then went silent. He'd had a heart attack and lapsed into a coma. The next night, as I waited in the hospital, I sobbed to my brother Jeff, "Fred can't die. Who will give Nate his shots?"—by which I meant injections of the medicines prescribed for him. Fred died that night. And two days later, I practiced giving injections by jabbing a naval orange. It was my first lesson as a single mom.

When Nate was 10, his language and motor skills were improving. Yet I somehow felt that he was capable of more, though I didn't know what "more" looked like. Open to anything, I visited a residence program outside of Boston where a friend's son was enrolled. I was impressed, but the idea of Nate living away from me was still a lot to grasp. So when an unexpected opening popped up two weeks later, I asked every teacher and other professional who had ever worked with Nate to weigh in. The consensus was, "Try it!"

About a week after I had enrolled Nate, I got a call from one of his teachers asking me to send a pair of sneakers with laces. "Why use laces when there's Velcro?" I asked. "Because learning to tie shoes is a life skill," the teacher told me. Ah, I thought, so this is what "more" looks like.

Nate enjoys cooking and helps to make meals at the Center for Discovery.

Joey would notice changes when we visited or brought Nate home. His brother had always confused the pronouns I and you. During one of Nate's visits, Joey said to me excitedly, "Did you hear that, Mom? Nate said, 'I want to play' instead of 'You want to play.' He's becoming unautistic!"

Nate would have remained at that residence if the state of New York hadn't curtailed its funding for out-of-state residential schools. After Nate returned home, I visited other potential places for him. Then I found the Center for Discovery. Located on 1,500 acres of rolling hills in New York's Hudson Valley, the center is home to residential and day programs for individuals with complex disabilities, medical frailties, and autism. During my tour, I learned that the residents' daily tasks might include feeding the goats, donkeys, and sheep, and recreation included swimming, horseback riding, and canoeing. The residents and staff seemed so happy! Again, the gods were with us. When a spot opened up a few weeks later, I didn't need help making my decision.

Nate moved to the center when he was 17. But there was no guarantee a permanent place would be available for him in the adult program once he

Besides making meals for those at the center, Nate also tends to the needs of the hungry four-legged residents.

turned 21 and aged out of the pediatric program. So when I received the call in 2011 asking if I wanted Nate to join the adult residence program for a lifetime placement, words failed me, though my heart screamed "Yes!"

Today, Nate shares a roomy three-story house with six other young men. Each has his own bedroom and bathroom. Nate helps with meal prep, does his laundry, cleans his room, and assists with the household chores. His Social Security and Medicaid benefits cover the cost. We live across the Hudson River, and Nate's wonderful stepdad, Rick, a blessed addition to his life, brings Nate home during holidays.

Nate's farm chores are varied and do indeed include feeding the goats and calves, gathering maple syrup, and harvesting vegetables. Nate is quite outgoing. He remembers the name of every person he has ever met—that is his photographic mind at work—so delivering the center's newsletters in town allows him plenty of opportunities to engage with the community. As for activities, the staff at the center has really set the bar high. Nate has learned ballroom dancing and yoga, and once when I called him, he told me he was reading the poem "Ozymandias" by the British poet Percy Bysshe Shelley. Then again, a week later he told me, "I'm eating pancakes. With tequila." His being so verbal is a blessing I have never taken for granted, particularly during the isolation periods of the pandemic, when we would chat almost daily.

There's a saying that goes, "If you've met one person with autism, you've met one person with autism." Each one is unique, as is his or her journey. Years ago, Joey said to me, "You know, Mom? If Nate wasn't autistic, he'd probably just be some surly teenager." Or today, at 31, some ever-texting, entitled millennial. I'll take Nate just the way he is. Recently we got word that he's been cast in the center's upcoming performance of *Cats*. If I close my eyes, I can see and hear Nate now: "Memory, all alone in the moonlight…Andrea." ◻

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Autism

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Autism Resources

These are some of the groups dedicated to advocacy and research.

Autism National Committee
autcom.org

Autism Network International
autismnetworkinternational.org

Autism Society of America
autismsociety.org

Autism Speaks
autismspeaks.org

The Autistic Self Advocacy Network
autisticadvocacy.org

The Organization for Autism Research
researchautism.org

Being Heard

Joshie Harris is nonverbal, and his father, Dan, was worried his son couldn't properly share his thoughts. So the elder Harris founded a charity called Neurodiversity in Business, and to help Joshie and others, he arranged for autism communication picture boards to be installed in communities like their hometown of Peterborough, England. Dan also raised funds to purchase and distribute 200 devices called Talkers. That way, those like Joshie, 11, can use tablets to communicate. The devices need to be regularly charged, though. To make sure he can always talk with his son, Dan had an alphabet grid tattooed on his arm so Joshie can easily let him know what he needs—as when "he tells us he wants ice cream, and he can spell it out on my arm."

Understanding Autism

More is known about neurodivergence than ever before, and the varying journeys have added to the tapestry of human experience.